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A Joint Specific Needs Assessment: Dementia in Leicester

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A Joint Specific Health Needs Assessment on dementia in Leicester

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Executive summary

Introduction

The development of health and social care for people with dementia is a key concern for Leicester. This Joint Specific Needs Assessment (JSpNA) is an overview of dementia care for the Leicester population. It highlights key issues and provides an indication of the likely level of need for those with dementia and their carers in the city. The following are some of the key points that can be drawn from this need assessment.

Methods

This Joint Specific Needs Assessment systematically reviewed the health issues within Leicester city of people with dementia and their carers. It assesses the impact of Dementia across Leicester, maps the current services, reviews effectiveness and summarises these findings.

Key Findings:

Population Affected

There are approximately 3,200 people with dementia in Leicester, with about 800 new cases occurring each year. Most people with dementia are aged 65 and over, but there are about 70 younger people with dementia. If dementia could be removed from the population about 250 deaths per year in those aged over 65 years could be averted.

The risk of having dementia thus increases with age, affecting 7.6% of the population aged 65 years and over. It is estimated that by 2030 the total number of people in this age group in Leicester will have risen by around 2%, from 35,400 to 51,300. In the same period it is also estimated that the number old elderly, those aged over 90 years, will more than double to 3,700 people.

Currently the vast majority of people aged over 65 years live in the community; 13,294 people in this age-group live alone and 1,250 live in care homes. Of the people aged over 65 with dementia living in Leicester it is estimated that 1,654 live in the community and 985 live in care homes. A high proportion of people aged over 65 years who live in care homes have dementia. The risk of a person living in a care home with dementia increases with age, such that more than 60% of those with dementia aged over 90 years are resident in a care home.

With regard to area of residence, most people over 65 years are resident on the outskirts of the city. There are many ward areas with more than 1,500 residents aged over 65 years. Knighton and New Parks wards have the highest number, whilst Evington and Thurncourt have the largest proportion of residents aged over 65 years.

Although Leicester is a diverse city, there are small numbers of people aged over 65 from black and minority ethnic (BME) backgrounds relative to the general population, but this is likely to increase substantially in future years.

Types of dementia

The term dementia describes a set of symptoms, including memory loss, mood changes, and problems with communication and reasoning. These symptoms are more severe than those experienced in normal ageing and occur when the brain is damaged by certain conditions, such as Alzheimer's disease, or a series of small strokes. The symptoms gradually get worse, with different needs emerging as the illness progresses. The severity of dementia can be categorised as mild, moderate or severe. Of the different types of dementia Alzheimer’s disease is the most common, accounting for more than 60% of all cases; dementia related to vascular disease is the next most frequent (17%). A further 10% of cases are related to a combination of the 2. The mean survival with Alzheimer’s disease is 7.1 years and 3.9 years with vascular dementia.

Service development

There are a number of services in Leicester currently delivering care for people with dementia and their carers. These include a memory assessment service, secondary care at University Hospitals Leicester and at Leicestershire Partnership Trust, primary and community health and social care services and local nursing and residential homes. However, there has never been a fully commissioned dementia care pathway. Current service provision has evolved often as a result of expertise on the ground rather than being commissioned effectively from the perspective of a patient’s journey. There is a clear need for this to improve in order to meet the challenge of developing local services to meet the population need.

Delivering the *National Dementia Strategy* should help to meet this challenge. There are 5 local work streams aimed at developing services so that all people with dementia and their carers should live well with dementia. These groups report to the Leicester, Leicestershire and Rutland Joint Dementia Commissioning Group and include:

- Early diagnosis and access to care and support services
- Improved experience of hospital care
- Improved quality of care in residential/care homes work stream
- Personalisation of care and living well with dementia in the community work stream
- A workforce fit to deliver services to support the care pathway for dementia

A local dementia care strategy has been developed by a group of lead commissioners across health and adult social care. A joint commissioning approach to the problem of developing dementia care services is vital for the development of priority areas where partnership would add value in terms of improved outcomes and greater efficiencies. The aim of the joint commissioning group is to implement change which meets local needs, consistent with the national strategy and the wider policy context relevant to dementia care, including *Putting People First*, the *Carers’*

Strategy, the *End of Life Care Strategy* and the strategic shift to prevention and early intervention.

In order to meet the dementia care needs of the local population, there is a requirement to improve rates of early diagnosis. Currently only 40-50% of the estimated population with dementia are recorded on primary care disease registers in Leicester. With earlier diagnosis people may be able to benefit from medication and obtain earlier access to important information relevant to people with dementia and their carers.

The improvement in rates of early diagnosis is not just about improving primary care. Better rates of early diagnosis and improvements in dementia care generally, can only be achieved by developing the whole dementia care pathway. Commissioning models requirements suggest that there is a requirement for more staff focused on dementia care, and more investment in memory assessment services, general hospital liaison care and care for people living in the community.

Early diagnosis is likely to have an impact on prescribing rates. There is already a general upward trend in the cost of prescribing drugs for dementia in Leicester, including medications, such as the acetylcholinesterase inhibiting drugs, which have some therapeutic effect on Alzheimer's disease. Whilst the patent to one of these drugs expired in February 2012, making the medication less expensive, recent NICE guidance releasing Memantine for cases of moderate to severe dementia is a risk to prescribing budgets.

Carers

The health and wellbeing of carers is also an immediate urgent need. Early diagnosis will allow more timely access to information about dementia. It should also give patients and carers the opportunity to look at support options. These options are likely to be tied closely to the agenda for personalised budgets, respite care, care home support and end of life care. These factors mean more social care developments, better training for all of those involved in dementia care and closer working relationships between clinical staff and dementia care co-ordinators.

Thus is important that the dementia care pathway offers support which maintains independence, enabling those who wish to remain at home to do so if they can. There should be a flexible approach to respite; including enough respite in the home where a person with dementia is less likely to become confused, and a carer may be able to take time away from caring responsibilities. As there are high rates of physical and mental health problems amongst carers, it is also important for carers to have access to regular reviews of their health and wellbeing.

Finally, whilst dementia clearly impacts most on those people aged more than 65 years, specific attention needs to be paid to those people, about 1% of the population, who are under 65 and have early on-set dementia.

Mark Wheatley, June 2012

Recommendations

The following recommendations have been made for consideration by the Joint Strategic Needs Assessment Board and commissioners:

1. Policy implementation

Local organisations involved in dementia care, should follow the lead of the local authority in supporting the outcomes of the *National Dementia Declaration*.

Local implementation of the *National Dementia Strategy* should establish links to other relevant policies and initiatives; such as the *End of Life Strategy*, the *Falls Strategy*, the *Dignity in Care Campaign*, and local voluntary sector initiatives such as the Dementia Action Alliance.

2. Recommendations with regard to Primary Care

To note the observed and expected rate of dementia by general practice locality.

A primary care model supporting early diagnosis should be developed in which GPs are encouraged to use a cognitive assessment tool, watchful waiting of potential cases, referral for blood tests and brain scans, and referral to the Memory Assessment Service.

There should be shared care arrangements between primary and secondary care to enable people with dementia to have access to appropriate care in the community; including advice on medications, clear definitions about who is able to prescribe; and information about how support activities of living.

There should be an improvement in the number of people with dementia whose care has been reviewed by their GP in the previous 15 months.

GPs should better identify and meet the needs of carers. In order to facilitate this, commissioners should monitor GP QOF registers of carers.

All carers should be invited by GPs for an optional annual health check.

Recommendation: All primary care staff should have training about the needs of people with dementia and their carers appropriate to their role in the Dementia Care Pathway.

Primary care should participate in the review of anti-psychotic medication for people with dementia, in the context of the support required for providing non-drug treatments and a review of the skills available for managing people with dementia in care homes.

Recommendation: Members of the primary care team, including reception staff, should receive appropriate training to respond appropriately to people with dementia and their carers.

3. Recommendations for the development of the memory assessment service

The Memory Assessment Service should be properly commissioned, incorporating methods of review and challenge to monitor effectiveness. Effectiveness should be measured on: increasing the rate of diagnosis (to 80% in 3 years), increasing the proportion of people diagnosed with dementia whilst they are in the early stages of the disease and increasing the number of carers who have a positive service experience.

Recommendation: As a specialist service the Memory Assessment Service should be commissioned to focus on individuals presenting in primary care with symptoms of mild to moderate dementia (Cluster 18) and the treatment of those people in whom the disease has significantly altered (Clusters 19 and 20).

The Memory Assessment Service provider should engage with commissioners and primary care to develop shared care agreements so that people with dementia will have access to the treatment and care they require.

4. Social care developments

To ensure that people diagnosed with dementia, who are eligible for support, are given a personal budget. Those who are not eligible should be given appropriate advice and information.

The dementia care co-ordinators should be commissioned solely to work with people with dementia and their carers. Their role should be to provide advice and support across the patient pathway. Access to the service should be from a number of points, including self-referral, voluntary sector organisations, primary, secondary and social care. To engage better with primary care, there should be closer links between dementia care co-ordinators and GPs in their different localities.

Recommendation: All nursing and residential home staff should have training about the needs of people with dementia and their carers appropriate to their role in the Dementia Care Pathway.

There should be a specialist community care team to assess the needs of people with dementia living at home or in care homes. This team will advise carers and other local health and social care providers about assessment and management interventions for patients with problematic symptoms of dementia.

5. Secondary Care

Recommendation: Commissioners should find ways of obtaining more effective coding of the attendance of patients with dementia at the emergency department.

Recommendation: To develop an integrated service comprising mental and physical health care expertise to provide a standard approach to the assessment and recording of an older person's mental health status upon admission to secondary care.

Recommendation: The multi-disciplinary hospital liaison service should incorporate credible mental and physical health expertise to assess the needs of frail older people. This team will facilitate detection of dementia in hospitalised group of patients, by reviewing them, prioritising patients' needs and reduce the length of stay of patients with cognitive issues. Patients diagnosed by the team should be added to the dementia register held in primary care.

Recommendation: LPT patients should be analysed, under the new payment by results tariff in mental health services, to provide a greater level of understanding as to the appropriateness of discharge to care homes and the alternatives that could be considered/developed in the future spanning both health and social care options.

Recommendation: Members of the secondary care team, including reception staff, should receive appropriate training to respond appropriately to people with dementia and their carers.

6. Community health care services

To ensure that there is an integrated reablement and integrated care model that reflects the needs of people with dementia.

7. Community mental health care

To review the existing ICATS model of delivery, to develop a service focused on preventing admission to the older person's mental health inpatient wards, and facilitate timely discharge from in-patient care.

To review the options for commissioning a joint health and social care crisis response service, to support both users and their families/carers.

8. Supporting carers in Leicester

Recommendation: All carers should have a carer's assessment

Recommendation: Carers' assessments should include information about breaks options.

Recommendation: There should be a wide variety of models of respite care tailored to individual needs and available to carers using personalised budgets.

1. Introduction

What is a Joint Specific Needs Assessment (JSpNA)?

The JSpNA is a systematic method for reviewing the local health and social care needs of a population facing a specific issue, in this case, dementia. The JSpNA will lead to agreed priorities and actions which will improve the circumstances of those people with dementia and their carers. It will be used to inform the dementia commissioning plans and future local dementia care strategies and is part of the wider Leicester Joint Strategic Needs Assessment programme (http://www.oneleicester.com/leicester-partnership/jsna/).

Objectives

The objectives of this specific needs assessment are those which were set out in the original JSpNA Brief, and cover:

- A summary of the national and local policy and strategic background;
- A description of the population at risk of dementia, highlighting particular characteristics relevant to Leicester;
- An estimation of the current incidence and prevalence of dementia;
- An assessment of impact of dementia on individuals, families, carers and communities;
- A summary of evidence and guidance of effective prevention, treatment and care;
- A description and assessment, against evidence and best practice, of the current response to need in Leicester - including strategic approach, prevention, models of care, capacity, costs, usage and outcome;
- The identification of gaps and issues in services and interventions;
- A forecast of numbers affected and future population need;
- An indication of the strengths and limitations of the needs assessment;
- Recommendations.

In meeting these objectives, this needs assessment will aim to:

- Make best use of existing evidence and experience;
- Complement the *National Dementia Strategy*, not duplicate it;
- Ensure that the final product is relevant to its audience;
- Provide data and information that is locally relevant;
- Appropriately engage providers, service users and relevant voluntary organisations and groups;
- Contribute to future needs assessment through sharing lessons learned in the process of completion

Literature used

In order to meet the objectives of the JSpNA the literature used has been classified, adopting the categories developed by Shekelle et al[1] which are shown in the Table below. The category of evidence is recorded with each new reference in the text.

Table 1: Classification schemes for categories of evidence

Categories of evidence	
Ia	Evidence from meta-analysis of randomised controlled trials.
Ib	Evidence from at least one randomised controlled trial.
Iia	Evidence from at least one controlled study without randomisation.
Iib	Evidence from at least one other type of quasi-experimental study.
III	Evidence from non-experimental descriptive studies, such as comparative studies, correlation studies and case control studies.
IV	Evidence from expert committees' reports or opinions and/or clinical experience of respected authorities

What is dementia?

Dementia may be subdivided into different diagnostic categories. It is defined in the International Classification of Diseases, 10th revision, (ICD-10)[2] as a syndrome resulting from disease of the brain. It is usually chronic, progressive and results in impairment of multiple higher cortical functions. These impairments, usually of faculties such as memory, thinking and orientation, are commonly accompanied by deterioration in emotional control, social behaviour and motivation.

The potential impact of dementia can be seen when one considers that the brain is responsible for producing a person's every thought, action, memory and feeling; these are explained further in Appendix 1. Changes, related to normal ageing, occur in the brain as a person gets older[3]; these may mean that there is a slight decline in an older person's ability to learn new things or remember information. However, the changes which are related to dementia are more severe.

In order to inform the organisation of support services, and as dementia related diseases are progressive, dementias may be classified as mild, moderate or severe[4].

- Mild: Mild cognitive decline shows problems in memory, concentration, remembering words or names, misplacing objects, difficulty in planning and performing tasks
- Moderate: Moderate cognitive decline includes forgetfulness of recent events and own history, impaired ability to undertake complex tasks, e.g. managing

finances. There are also noticeable gaps in memory and thinking, confusion about what day it is, being unable to remember own address and phone number, need for help in day-to-day activities
- Severe: Severe cognitive decline demonstrates worsening memory, loss of awareness of recent experiences and surroundings and may show behavioural changes. Individuals distinguish between familiar and unfamiliar faces but have difficulty remembering names, will need help dressing and toileting and tend to wander and become lost. In the final stages, individuals are unable to respond to their environment, to hold a conversation and will need help with much of their daily personal care

Diagnostic classification is important because the causes and treatments are different. Although treatment can slow the progression of dementia and help manage the symptoms in some people, currently there is no cure. The most frequently observed dementias are caused by plaques and tangles in the brain (Alzheimer's disease), the loss of connections between nerve cells in the brain (Alzheimer's disease, dementia with Lewy bodies) or the disruption in the blood supply to the brain (vascular dementia). Rarer causes can be genetic (Huntingdon's disease), or from alcohol misuse (Wernicke-Korsakoff disease) or infection (Creutzfeldt-Jakob Disease).

Alzheimer's disease is a degenerative cerebral disease which disrupts the processes that keep neurons healthy. The brains of people with Alzheimer's disease have characteristic neuro-pathological and neuro-chemical features. In particular, there are amyloid plaques and neurofibrillary tangles which are made of misfolded proteins, in those areas of the brain that are important for memory. Depending on their location in the brain, these plaques, proteins and tangles, will progressively undermine the ability of a person with Alzheimer's disease to undertake certain functions.

The clinical features of Alzheimer's disease include the following:

- Insidious onset, usually in late life with gradual development over a period of years
- Brain pathology with progressive loss of neurons leading to cerebral atrophy
- Progression apparent as increasing impairment of memory storage and retrieval, going on to global disorder of cognition, orientation, linguistic ability and judgement
- A clinical course which is accompanied by growing disability and dependency on care
- A variable rate of progression.

Vascular dementia refers to dementia which is caused by changes to the blood supply to the brain. It is also called arteriosclerotic or multi-infarct dementia and it is distinguished from Alzheimer's disease by its clinical features and course. It is common for mixed forms of vascular and Alzheimer's-type dementia to occur in people of older ages.

Typically vascular dementia is characterised by:

- A history of transient ischaemic attacks, intermittent disruption of blood supply to the brain; these could result in brief impairment of consciousness, fleeting pareses (inability to move) or visual loss
- Dementia following a succession of acute cerebrovascular accidents (strokes) or, less commonly, a single major stroke
- Mental deterioration resulting from a brain infarct, the death of brain cells, related to cerebrovascular disease; the individual lesions usually being small but cumulative in their effect.

Dementia with Lewy bodies[5]**:** Lewy bodies are tiny, spherical protein deposits, found in neurons, which disrupt the brain's normal functioning by interrupting the action of chemical transmitters such as acetylcholine and dopamine. Most cases of people with dementia with Lewy bodies were found to have Lewy bodies in the brain stem and the cerebral cortex[6].

The symptoms of Dementia with Lewy Bodies are similar to Alzheimer's and Parkinson's diseases[7]. Indeed, Lewy bodies are usually found in the brain stems of people with Parkinson's disease, a progressive neurological disease that affects movement. A third of people with Parkinson's disease develop dementia and a third of people with Alzheimer's disease show evidence of Parkinsonism[8]. The aetiology of the disease is complex, but the onset is usually in old age and it is usually characterised by clinical features such as:

- Fluctuation in the level of cognitive impairment
- Visual and auditory hallucinations
- Paranoid delusions
- Depressive symptoms
- Falls or unexplained episodes of loss of consciousness.

Frontotemporal disorders result from damage to neurons in the frontal and temporal lobes of the brain. Gradually this damage may cause emotional problems, difficulties with communication, behaviour, recognising danger, walking and other movements. Frontotemporal disorders can be grouped into different types which encompass these symptoms[9].

- Progressive behaviour/personality decline (such as in Pick's disease), characterised by apathy, reduced initiative, inappropriate and impulsive behaviour and emotional flatness or excess.
- Progressive language decline: For instance having difficulty understanding words, having difficulty in finding the right words, omitting words from sentences and difficulty in swallowing.
- Progressive motor decline: This includes Corticobasal syndrome, which is characterised by muscle rigidity, language or spatial orientation problems, problems operating simple appliances, problems with balance and walking, restricted eye movements, body stiffness.
- Frontotemporal disorder with Parkinson's disease includes slowed and stiff movement marked by Parkinson's disease.

- Frontotemporal disorder with amyotrophic lateral sclerosis (Lou Gehrig's disease) has symptoms such as muscle weakness, jerking and changes in behaviour and language.

Delirium is distinct from, but commonly associated with, dementia. It is a state characterised by:

- Fluctuating mental confusion, with reduced alertness and attention
- Disorders of perception, including misinterpretation of one's surroundings and, in many cases, fearfulness and agitation
- Tremor, sweating and tachycardia
- Coma in severe cases.

The causes of delirium include infection, cardiac failure and rapid withdrawal of alcohol or drugs. There may be an underlying predisposition related to old age and cognition. Although most episodes of acute or sub-acute delirium are responsive to medical treatment, the presence of underlying dementia in some cases means that there is a vulnerability to further episodes of delirium.

Early-onset dementias are those which affect people under the age of 65. Whilst Alzheimer's disease accounts for some of these cases, other causes, including those related to genetic conditions, are also important. For instance, people with Down's syndrome are at an increased risk for Alzheimer's disease. A survey of people with Down's syndrome[10] estimated that the prevalence of dementia was 3.4% in those between 30–39 years and 40% at 50–59 years. Other conditions which are associated with the early onset of dementia include Huntington's disease and acquired brain injury[11]. Early onset dementia is also associated with HIV-AIDS and Creutzfeldt - Jakob disease.

Some people may be identified as having symptoms of cognitive decline which do not meet clinical criteria for the diagnosis of dementia. In such cases there may be a diagnosis of ***mild cognitive impairment (MCI)***[12]. The definition of MCI used within the National Institute for Health and Clinical Excellence (NICE) clinical guideline CG42 on dementia[13] is that it is a syndrome defined as cognitive decline greater than expected for an individual's age and level of education but which does not interfere notably with activities of daily life.

A proportion of people with MCI have been shown to develop some form of dementia over time. The rate of conversion from MCI to dementia depends on the diagnostic criteria used, the type of cohort studied and the length of observation time from diagnosis of MCI[14]. For people with MCI who are referred to memory assessment services and other specialist centres, the rate of conversion to dementia has been estimated to be around 18% per year[15]. Several different types of MCI have been proposed[16] [17]. Studies estimate that prevalence of MCI is between 5% and 25% in older people[18] [19] [20]. However, most people with MCI, or subjective memory impairment, may present with symptoms other than cognitive impairment or do not report any symptoms.

Costs of dementia

Estimating the overall financial cost of care for people with dementia is difficult. They cut across all services, for instance the extent of the problem, often missed by health and social care services, can be seen in the impact that people with dementia have had on the work of the police. The Comprehensive Referral Desk of Leicestershire Police, established with a remit which includes providing a cohesive and comprehensive police approach to safeguarding adults at risk of harm[21], reports that on average there are between 40 and 50 cases per month of people with dementia who require assistance from the police in Leicestershire.

People with dementia depend on informal care for much of the time, but even when they have formal care, for instance when they require care of an acute physical illness, the presence of a dementia is often not recorded. *Dementia UK*[22] found that the total costs of dementia in 2007 amounted to £17.03 billion per annum, or an average of £25,472 per person with late onset dementia. Since 2007 the total cost of dementia has continued to rise: updated figures for 2010 put the cost at £20 billion with 750 000 people living with the condition.

The total annual cost per person with dementia in different settings is estimated as follows[23] on the Alzheimer's society website:

- People in the community with mild dementia - £14,540
- People in the community with moderate dementia - £20,355
- People in the community with severe dementia - £28,527
- People in care homes - £31,263.

These costs include those provided by formal care agencies as well as the financial value of unpaid informal care provided by family and friends. Costs were not available for the 2% of people with dementia under the age of 65. Over a third of the total cost (36%) was due to informal care; including an estimated £690 million in lost income for those carers who have to give up employment or cut back their work hours. This lost employment means a loss of £123 million in taxes paid to the Exchequer. Accommodation accounted for 41% of the total cost, with the greatest proportion of direct costs of dementia care associated with institutional support in care homes. This is often provided at a crisis point, is always costly and often precipitated by a lack of effective support. The King's Fund Report *Paying the Price,*[24] projects that the cost of dementia in England will increase by 135% from £14.8 billion in 2007 to £34.8 billion in 2026.

As most packages of care for people with dementia are typically provided through social services and are means tested, people with dementia often pay significant amounts towards their care. This places the burden of cost of care heavily on people with dementia and their families. Average residential care home costs in the UK are £479 per week, while average nursing home costs are £669 per week. Alzheimer's Society's 2008 found that the impact of charging for care cuts across all socio-economic groups and is not confined to people of moderate and higher means; the Alzheimer's Society called this the Dementia Tax. The *Dementia UK Report* also found many people are not receiving the quality of care they deserve and often have to pay substantial amounts of money for poor quality care.

The Alzheimer's Society's has a position on charging for care which supports a new system of funding and charging for care which:

- Ends the dementia tax and moves to a system where risk is shared beyond people with a specific medical condition like dementia.
- Delivers good quality care at a fair price.
- Abolishes the current fair access to care system, which means no one with lower level or moderate needs gets help.
- Recognises the role of unpaid carers and ensures that they are not financially disadvantaged by caring.
- Delivers consensus across our political parties, similar to that achieved over pensions policy.
- Provides early intervention and good quality care for all.
- Where the state to provides a minimum level of care free to all. The basic package should incorporate guarantees about the care to be provided. Access to early intervention services, regular respite care and a guarantee that care will be of high quality are particularly important.
- A flexible system which allowed people with different levels of need to access different packages of state funded care[25].

As dementia is one of the major challenges facing modern Britain, there has been a move to ensure that concerted action is taken to improve dementia care, which has resulted in the *Dementia Action Alliance* and the *National Dementia Declaration*. This declaration contains seven desired outcomes for people with dementia and their carers:

1. I have personal choice and control or influence over decisions about me
2. I know that services are designed around me and my needs
3. I have support that helps me live my life
4. I have knowledge and know-how to get what I need
5. I live in an enabling and supportive environment where I feel valued and understood
6. I have a sense of belonging and of being a valued part of family, community and civic life
7. I know there is research going on which delivers a better life for me now and hope for the future[26].

There are a number of signatories to the declaration, including Leicester City Council[27]. The local authority vision for the declaration is that for all people with dementia and their family carers to be able to continue to live a full, active and independent life in the community.

To do this the local authority aims to provide local leadership to organisations within Leicester to create an environment which is supportive of the needs of people with dementia and their family carers. The local authority is also committed to work in partnership to commission high quality based on evidence of need and of what works best for those living with dementia and their family carers.

Success will mean that the stigma attached to dementia is decreased; that people feel empowered to seek help early; will know where to go for support and what services to expect; will have access to high quality care and support; and that professionals feel well informed.

Key challenges for Leicester, expressed by the local authority are:

- Winning the hearts and minds of all stakeholders about what is possible for people with dementia and putting them in control of choices about how they wish to live their life.
- Ensuring that staff working across the City Council and its partner organisations has the appropriate skills and knowledge to enable them to serve all citizens, including those with dementia.
- The impact on health and social care as a result of the savings which must be made to public sector finances.
- The need to maintain and improve joint working arrangements with NHS partners for commissioning and delivery, at a time when these partners are undergoing significant structural change.

The Local Authority plans to improve dementia care between now and 2014 include the development of a Leicester City specific strategy, taking forward the activities of the work streams, each with its own action plan.

Recommendation: Local organisations involved in dementia care, follow the lead of the local authority in supporting the outcomes of the National Dementia Declaration.

2. Policy Background

2.1 National Policy

The National Dementia Strategy (NDS) *Living Well with Dementia*[28] sets out a vision for a health and social care system in which people with dementia and their carers have access to beneficial care and support. It suggests that, with the collaboration of health and social care services, the third sector and carers, much can be done to maintain and improve the quality of life of people with dementia. In order to achieve this, however, there is a need to overcome the boundaries between health, social care and the third sector.

Politically, dealing with the issue of dementia has been further endorsed by the *Prime Minister's challenge on dementia*[29]. In this the Prime Minister states that he is "determined that we will go further and faster on dementia – making life better for people with dementia and their carers, and supporting the research that will ultimately help us slow, stop and even prevent the condition."

The key commitments in the challenge include, increased diagnosis rates through regular checks for over-65s, financial rewards for hospitals offering quality dementia care, improving standards care homes and domiciliary care better support for cares and better information for people with dementia and their carers (See Appendix 11).

When the strategy was published it was consistent with the wider policy context likely to be relevant to people affected by dementia. It was suggested that these policies would also strengthen the commissioning and delivery of services to people with dementia and their carers. The relevant other strategic initiatives included *Putting People First*[30], *Think Local, Act Personal*[31] the *Carers' Strategy*[32], the *End of Life Care Strategy* [33] and the strategic shift to prevention and early intervention. *The Dignity in Care* campaign and improvements flowing from the consultation on adult safeguarding were also pertinent to the vision set out in the NDS.

The NDS itself outlined 17 objectives to improve the quality of life for people with dementia and their carers. The objectives were presented in three broad themes:

- raising awareness and understanding
- early diagnosis and support
- living well with dementia

The objectives are presented in full in Appendix 2. In summary raising awareness of dementia will help to remove the stigma suffered by people with dementia and their carers and reduce fear and misunderstanding. More early diagnosis is intended to enable people with dementia and their carers to gain timely access to benefits and treatment. Living well with dementia includes a focus on improving carer support, and improvement in care along the whole dementia care pathway, including helping people to stay at home for longer if they so wished.

The NDS notes that these objectives had to be supported by actions to develop the workforce, plans to enable joint commissioning, and improved monitoring of services, evaluation and implementation. Following public consultation an Implementation Plan was developed, which set out the tasks ahead. This plan currently underpins the approach to joint commissioning for dementia care services.

Whilst this plan is not prescriptive, in that it does not suggest which services should be planned, commissioned, provided and delivered, it shows how the Department of Health will provide support nationally and regionally. The pace of implementation will inevitably vary depending on local circumstances and the level and development of services within each NHS and Local Authority area. The Implementation Plan describes the arrangements for what the Department of Health will do as an enabler for continued progress towards meeting all 17 objectives in the Strategy

The consultations confirmed the need for early diagnosis and intervention. Although some people argued that it is better not to tell someone if they have dementia, most believed they should have the right to be told. However, the consultations suggested that, despite this, people are currently likely to see specialist services at a point where there is little chance of specialist input improving their quality of life.

Other examples of suggested service improvements which emerged during the consultations included:

- GPs working side by side with mental health services
- GPs knowing how to spot the first signs of dementia
- Having one person who is responsible for dementia services in hospital
- Giving everyone with dementia their own personal dementia adviser to help them
- Helping people with dementia to stay in their own homes for longer

Given the progressive nature of dementia, the links between the NDS and the *End of Life Care Strategy* are clear. The *End of Life Care Strategy* suggests that as a society we do not discuss death and dying openly. It looks at caring for all people at the time of death, explaining that most deaths (58%) occur in NHS hospitals, with around 18% occurring at home, 17% in care homes, 4% in hospices and 3% elsewhere. This means that the demographics of death in relation to age profile, cause and place of death have changed over the course of the past century. At the beginning of the 20th century most people died in their own homes, acute infections were a much more frequent cause of death and a far higher proportion of all deaths occurred in childhood or early adult life.

The assumption behind the *End of Life Care Strategy* is that whilst some people die as they would have wished, receiving care in hospitals, hospices, care homes and in their own homes, many do not. Many people experience unnecessary pain and other avoidable symptoms. Some are not treated with dignity and respect, and many people do not die where they would choose.

In the light of this, the *End of Life Care Strategy* aims to ensure that people have the opportunity to discuss their personal needs and preferences with professionals. It is envisaged that all health and social care staff will be trained in communication regarding end of life care, in assessing the needs of patients and carers and, where necessary, reconciling differing requirements. Thus, according to the *End of Life Care Strategy* the discussions of preferences will be recorded in a care plan so that every service involved will be aware of peoples' priorities and will take account of their preferences. The aim of recording such needs and preferences in a care plan is to coordinate care and support; ensuring that needs are met, irrespective of who is delivering the service.

The *End of Life Care Strategy* envisages a rapid specialist advice and clinical assessment wherever a patient may be, including access to dedicated 24/7 telephone help lines and rapid access homecare services and specialist palliative care outreach services to be established in every area. The *End of Life Care Strategy* is discussed in more detail in Appendix 3.

The *Dignity in Care Campaign*[34] aims to put dignity and respect at the heart of care services. Over 23,000 people have now joined the campaign as Dignity Champions; that is those people who have signed up in support of the need to deliver care services that respect dignity. They are part of a nationwide movement, working individually and collectively, to ensure people have a good experience of care when they need it. They include councillors, staff at all levels in NHS and social care, volunteers, service users, their carers and members of the public.

The campaign is about winning hearts and minds, changing the culture of care services and placing a greater emphasis on improving the quality of care and the experience of people using services including NHS hospitals, community services, care homes and home support services. It includes action to raise awareness of dignity in care and inspire local people to take action. Such actions include sharing good practice, innovation and transforming services by supporting people who make a difference

Carers feature largely in the key requirements of any dementia related service. They are also a high priority for the Coalition Government. The *Think Local, Act Personal* initiative, includes a qualitative review for carers in general, and *Recognised, valued and supported* focuses on the next steps for the Carers Strategy[35]. These next steps include some which fit well with the people involved in caring for those with dementia.

The first priority area is ***identification and recognition of carers at an early stage***. This recognises the value of the contribution of carers and aims at involving them from the outset in the design and planning of care. It is congruent with carers of people with dementia and the need for early diagnosis. One of the main problems with identifying a person as a carer is that many carers do not identify themselves as such until they have been caring for a number of years[36]. This often happens when the caring role gradually develops, or because carers may find it difficult to find time and energy to reflect on the future. One advantage of involving carers in planning care is that they are able to give expert understanding about the needs of the person for whom they are caring. Involving carers in the arrangements for planning a discharge from hospital, for example, may be important in reducing readmissions.

Another next step is ***helping carers to realise their potential*** (looking for instance at the number of carers at work or in education). This would include support for people who are at work and who also care for someone with dementia. This is where support for carers touches on wider legislation such as the Equality Act 2010, which recognised the vital role that carers play and the disadvantages which they may experience. Such legislation strengthens the protection of carers against discrimination in the workplace and when accessing services.

A vision for adult social care: Capable communities and active citizens[37] suggests that a plurality of providers should be available to match a variety of needs, including the needs of carers who require high quality care to enable them to work. Many carers consider that it is important for their own personal and financial wellbeing to be able to continue to work. So carers should be encouraged and supported to return to work.

The *Next Steps for the Carers' Strategy* also focuses on ***carers having a life of their own outside caring***. This may depend on the context, but could mean the need for respite care or indeed the implementation of the personalisation agenda. Personalisation means that, as far as possible, all services and support available to carers should be tailored to their specific needs

Personalisation is seen as complementary to a 'whole-family' approach; an approach in which the views and cultural expectations are addressed and clarified when considering how to support a family. Personalisation will provide individuals, families and carers with more choice, control and flexibility[38]. *A vision for adult social care* makes clear that councils should provide everyone who is eligible with a personal budget, preferably as a direct payment, by April 2013.

Whilst personalisation and personal budgets can take many forms, there is an anxiety amongst older carers about managing finances and about whether there will be no services to buy. Unless they so wish, carers will neither have to conduct their own procurement of services, nor will they have to manage the financial arrangements. There are different approaches suggested for the management of personalised budgets, including the use of intermediaries, such as voluntary organisations, or other models such as trusts or individual service funds.

Recognised, valued and supported[39] emphasises that in a call for views in the summer of 2011, carers suggested that priority should be accorded to reducing the amount of time taken in the assessment of carers and the people that they support. In order to expedite the assessment process some local authorities have developed a system for training people in the voluntary sector as assessors. *Recognised valued and supported* suggests that the Department of Health recognises that there is a need for flexibility in conducting assessments and that it will consider this issue in the light of work conducted by the Law Commission and the Commission on the Funding of Care and Support[40] [41].

There are other initiatives which could be used to benefit carers. The QIPP (Quality, Innovation, Productivity and Prevention) programme could be relevant to supporting carers and the people they support. For instance QIPP long terms conditions work emphasises personalised care planning and supportive self-care in order to maximise independence and minimise unnecessary stays in hospital. QIPP end of life care has focused on improving the identification of people who are approaching the end of life as well as planning care.

Another priority area is *supporting carers to stay healthy*. There is a relationship between poor health and caring which increases with the duration and intensity of the caring role. According to Carers UK[42] carers are twice as likely to have poor health as those people who are not undertaking a caring role. This may be because of the psychological impact of caring, resulting from stigma, isolation, relationship problems and financial hardship. Carers are more likely to report high levels of psychological distress than non-carers, including anxiety, depression, loss of confidence and self-esteem[43]. Poor physical health is also associated with caring, with carers suffering high rates of hypertension, cardiac problems and musculo-skeletal problems[44].

Caring may exacerbate existing inequalities in health[45]. Of particular relevance to carers of people with dementia, looking after a spouse or a partner is particularly associated with additional health problems beyond those which may be attributable to other health inequalities[46]. *Recognised valued and supported* also advocates prevention and early intervention for carers; highlighting timely access to relevant information, support at key stages along the care pathway. It suggests that carers should be encouraged to receive a health check and there should be health and wellbeing activities targeted at carers.

Another important lever in the delivery of better care for people with dementia is the current objective, set out in the *Payment by Results quality and Outcomes Indicators*[47], to have currencies and local prices established and in use during 2012-13. Mental Health Care Clusters[48] for payment by results could help to classify mental health service provision. With regard to dementia there are 4 care clusters of interest, which could be used to describe the progress of the illness:

Care Cluster 18: Cognitive Impairment (Low Need) - People who may be in the early stages of dementia (or who may have an organic brain disorder affecting their cognitive function) who have some memory problems, or other low level cognitive impairment, but who are still managing to cope reasonably well. Underlying reversible physical causes of the impairment have been ruled out.

Care Cluster 19: Cognitive Impairment or Dementia Complicated (Moderate Need) - People who have problems with their memory, and/or other aspects of cognitive functioning resulting in moderate problems looking after themselves and maintaining social relationships. Probable risk of self-neglect or harm to others and may be experiencing some anxiety or depression.

Care Cluster 20: Cognitive Impairment or Dementia (High Need) - People with dementia who are having significant problems in looking after themselves and whose behaviour may challenge their carers or services. They may have high levels of anxiety or depression, psychotic symptoms, or significant problems such as aggression or agitation. They may not be aware of their problems. They are likely to be at high risk of self-neglect or harm to others, and there may be a significant risk of their care arrangements breaking down.

Care Cluster 21: Cognitive Impairment or Dementia (High Physical or Engagement) - People with cognitive impairment or dementia who are having significant problems in looking after themselves, and whose physical condition is becoming increasingly frail. They may not be aware of their problems and there may be a significant risk of their care arrangements breaking down.

2.2 Local implementation

In Leicester the current model of care for people with dementia and their carers consists of a mix of services which have either developed by custom and practice, as a result of clinical experience, or from piecemeal commissioning of discrete projects which have not taken into account the whole patient pathway or experience. In order to improve this, the Joint Dementia Commissioning Group has established 5 work streams focusing on 23 local objectives for Leicester, Leicestershire and Rutland. The 23 local objectives are set out in more detail in Appendix 5. The 5 work streams are:

- Early diagnosis and access to care and support services (led by NHS Leicester, Leicestershire and Rutland and Leicestershire Partnership Trust)
- Improved experience of hospital care (led by NHS Leicester, Leicestershire and Rutland and University Hospitals of Leicester)
- Improved quality of care in residential/care homes work stream (led by Leicestershire County Council)
- Personalisation of care and living well with dementia in the community work stream (led by Leicester City Council)
- A workforce fit to deliver services to support the care pathway for dementia (led by NHS Leicester, Leicestershire and Rutland workforce development team

The overall strategic direction of local implementation is linked to national policy and includes the main initiatives, such as:

- Increase the proportion of people with dementia receiving an early diagnosis
- Increase the proportion of people with dementia having a formal diagnosis
- Increase the number of patients and carers having a positive service experience
- Reduce average length of stay in hospital for patients with dementia
- Reduce number of people with dementia discharged directly from hospital to care homes as a new place of residence
- Reduce number of people discharged from hospital on antipsychotic medication, including a plan to review use of antipsychotic medication post discharge
- Reduce the use of antipsychotic medication for people with dementia
- Contribute to a reduction in unplanned admissions and readmissions of people with dementia to general and community hospitals
- Achieve better care at home and in residential care

The local care pathway is likely to cover a number of levels from pre-diagnosis right through to care home and hospital care, and is likely to include the following:

Community / Pre-diagnosis

- Advice and Information to the general public about symptoms such as memory loss and campaigns such as Stroke – Act F.A.S.T.[49]
- Prevention and early Intervention strategy
- General Practice to undertake cognitive tests such as ADAS COG or MMSE; watchful waiting, referral to Memory Assessment Service, reassurance
- Diagnostic tests; blood tests, brain scan and diagnosis of clear cut cases in primary care
- Opportunistic assessment of frail elderly attendees at UHL, diagnosis of clear cut cases

Interdependencies with other work

- LLR Carers Strategy
- Frail elderly programme

Level 1: Early diagnosis and low level support (Care Cluster 18)

- Memory Assessment pathway: LPT Memory Assessment Service
- Early diagnosis based on assessment, diagnostic tests
- Initiate drug therapies for people with Alzheimer's disease
- Shared care protocols between Memory Assessment and Primary Care
- Dementia Care Co-ordinators to provide access to advice and information
- Dementia Cafés
- Initial contact with Community Mental Healthcare Teams

Interdependencies with other work

- LLR Carers Strategy
- Carer health checks
- Frail elderly programme

Level 2: Moderate support at home (Care Cluster 19)

- Continued support from Dementia Care Co-ordinators, linked to Primary Care
- Consistent detection of cognitive impairment in General Practice
- Opportunistic assessment by general hospital liaison team
- Opportunistic late diagnosis
- Support for people with dementia and carers from Community Mental Health Care Teams when necessary
- Carers support and education
- Intermediate care at home

Interdependencies with other work

- LLR Carers Strategy
- Carer health checks

- Intermediate Care and reablement
- Frail elderly programme

Level 3: Intensive support at home (Care Cluster 20)

- Support from General Practice
- Expert input from Memory Assessment Service
- Assessment from general hospital liaison team
- Links to district nurse and community matron teams
- Community Mental Healthcare Teams
- Social care support for people in a crisis
- Respite care programmes for carers
- Continued support from Dementia Care Co-ordinators

Interdependencies with other work

- Review of ICAT
- Falls Strategy
- Intermediate Care & Reablement
- Frail elderly programme
- LLR Carers Strategy
- Carer health checks

Level 4: Care home / hospital care (Care Cluster 21)

- Support from General Practice
- Expert input from Memory Assessment Service if necessary
- Assessment from general hospital liaison team
- Links to district nurse and community matron teams
- Community Mental Healthcare Teams
- Social care support for people in a crisis
- Respite care programmes for carers
- Continued support from Dementia Care Co-ordinators
- Care for carers following death of person with dementia

Interdependencies with other work

- End of Life strategy
- Falls Strategy
- Intermediate care
- Frail elderly programme
- LLR Carers Strategy

Recommendation: Local implementation of the National Dementia Strategy should have established links to other relevant policies and initiatives, such as groups delivering the *End of Life Strategy*, the *Falls Strategy*, the *Dignity in Care Campaign*, and local voluntary sector initiatives such as the Dementia Action Alliance.

3. Population of Leicester

Leicester is the largest city in the East Midlands. It is a mainly urban area of 73.3 km with a population of 306,631[50]; it has a high population density of 4,182 people/km^2 49% of the population, 151,277 people, are male; 155,354 are female (51%). The population is predicted to increase to about 346,000 by 2020. Projections indicate that Leicester will have a smaller proportion of people aged below 10 years and a larger proportion over 40 years.

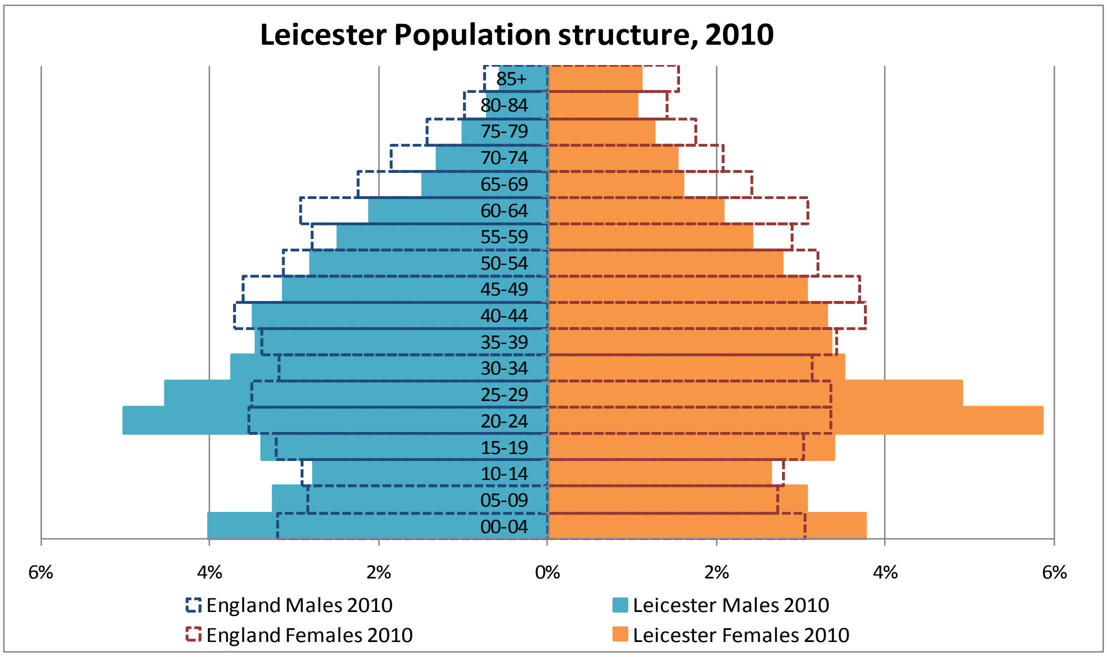
Average life expectancy in Leicester is lower than the average for England. Males in Leicester have an average life expectancy of 75.4 years (3 years below the England average) and females have an average life expectancy of 80.1 years (2.5 years below the England average).

3.1 Population structure of Leicester

Although Leicester is predicted to have a larger proportion of people aged over 40 years, currently the city has a relatively young population compared with the country as a whole, with a large proportion of the population aged below 40 years.

Numbers are particularly high for men and women aged 20-34, this may be due to inward migration of new communities and the large the student population who attend two universities. Only 11.6% of the population is aged 65 and over, equivalent to around 35,700 people, compared to around 16.5% for England as a whole.

Figure 1: Leicester Population structure, 2010



Data: Office for National Statistics (ONS) mid-2010 population estimates

3.2 Population over 65 years by ward area

Dementia disproportionately affects people aged 65 and over. The Leicester ward areas with the highest **number** of people aged over 65 years are Knighton and New Parks; each with over 2,000 people in this age group. The ward areas with the largest **proportions** of residents aged over 65 are Evington and Thurncourt, with around 20%.

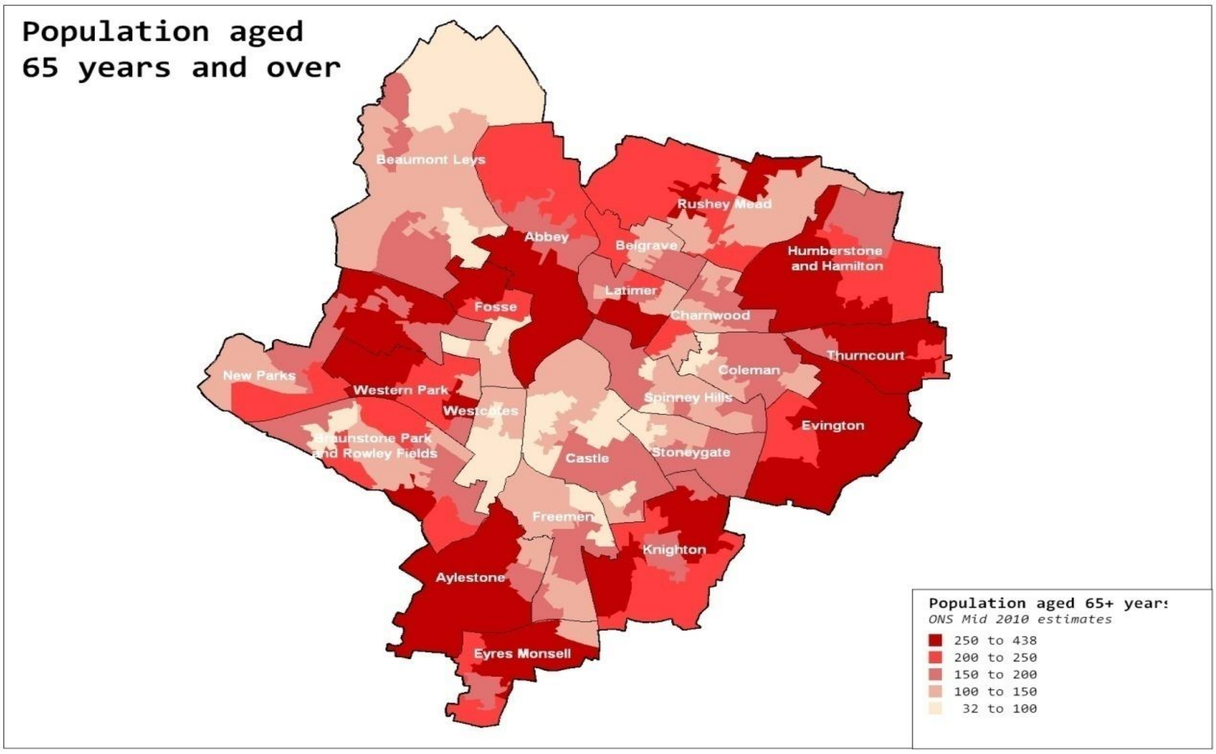
Table 3.1: Leicester Population aged 65+ by ward, 2010

Ward Name	All Ages	65-69	70-74	75-79	80-84	85+	Total 65+	% 65+
Abbey	13,770	460	438	367	365	290	1920	13.9%
Aylestone	10,826	429	409	334	291	338	1801	16.6%
Beaumont Leys	16,120	397	290	187	143	116	1133	7.0%
Belgrave	10,863	349	320	239	167	116	1191	11.0%
Braunstone Park and Rowley Fields	17,411	548	551	404	323	275	2101	12.1%
Castle	19,402	253	224	195	152	160	984	5.1%
Charnwood	12,272	372	302	172	141	109	1096	8.9%
Coleman	13,501	317	303	247	159	156	1182	8.8%
Evington	10,341	489	428	444	399	412	2172	21.0%
Eyres Monsell	11,530	394	423	374	300	255	1746	15.1%
Fosse	11,923	332	346	248	156	177	1259	10.6%
Freemen	10,310	242	269	171	128	142	952	9.2%
Humberstone and Hamilton	16,711	493	432	410	357	228	1920	11.5%
Knighton	15,592	673	611	549	516	475	2824	18.1%
Latimer	12,015	443	451	310	205	133	1542	12.8%
New Parks	16,667	608	517	395	325	413	2258	13.5%
Rushey Mead	15,845	626	571	442	272	249	2160	13.6%
Spinney Hills	21,832	581	528	378	202	204	1893	8.7%
Stoneygate	18,955	506	415	291	157	136	1505	7.9%
Thurncourt	10,019	454	455	454	337	278	1978	19.7%
Westcotes	9,312	177	141	110	100	71	599	6.4%
Western Park	9,505	333	290	274	271	292	1460	15.4%
Leicester	304,722	9,476	8,714	6,995	5,466	5,025	35,676	11.7%

Data: ONS mid-2010 population estimates

In general people aged over 65 years are resident in areas which are towards the outskirts of the city, particularly in the east and south, as shown in Figure 2 below. The need for dementia care is likely to be greater in these areas. This pattern of residence is also shown the by Mosaic Typology data (see pages 46-7)

Figure 2: Population aged 65 and over by lower Super Output Area in Leicester (LSOA)



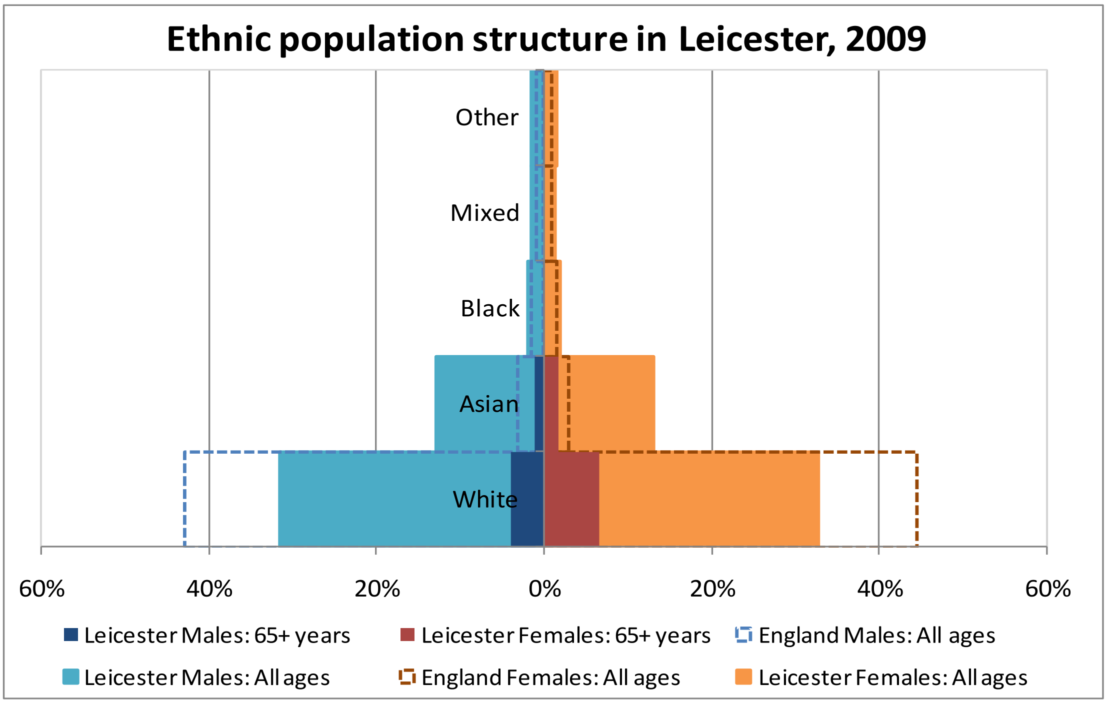
Data: ONS mid-2010 population estimates by LSOA

3.3 Ethnicity

When compared to the country as a whole, Leicester has a more ethnically diverse population. Office for National Statistics (ONS) population estimates show that Leicester has a Black and Minority Ethnic (BME) population of 36% whilst the proportion for England and Wales is 13%. The majority of Leicester's BME population are from South Asian backgrounds; this group comprises 26% of the total population of the city. Most of the people from South Asian ethnic backgrounds are from India; 19% of the city population. People from black or black British ethnic backgrounds make up 4%, mixed ethnic groups 3% and other ethnic groups 3%, of the population.

It is estimated that there may be as many as 150 languages and/or dialects spoken in Leicester. Gujerati, Katchi, Punjabi, Urdu and Bengali are widely spoken. There are increasing numbers of people who speak Eastern European languages, such as Polish or Slovak, and East African languages such as Somali.

Figure 3: Ethnic population structure in Leicester, 2009



Data: ONS mid-2009 ethnic population estimates

3.4 Ethnicity of people aged over 65 years

Whilst the city as a whole is ethnically diverse, the majority of the people aged over 65 years are from White or White British ethnic backgrounds, making up 10% or the total population. Over 65s from Asian ethnic groups make up only 3% and less than 1% of the population are from other BME groups. There is a higher proportion of elderly within the White group (16%), whilst other BME groups have relatively fewer over 65s; 11% of Asian and 9% of Black groups are over 65.

With the predicted increase in the number of people over 65 years, meeting the needs of older people from BME groups will become an urgent issue in the near future.

Table 3.2: Ethnic population of over 60/65s in Leicester, 2009

Ethnic group	Leicester Males: All ages	Leicester Males: 65+ years	Leicester Females: All ages	Leicester Females: 60+ years	Leicester: All ages	Leicester: F 60+/M 65+ years
White	95,800	11,800	99,600	20,200	195,400	32,000
Asian	39,300	3,100	40,100	5,300	79,400	8,400
Black	5,700	400	5,800	600	11,500	1,000
Mixed	4,400	0	4,300	0	8,700	0
Other	4,900	100	4,400	100	9,300	200
Total	150,100	15,400	154,200	26,200	304,300	41,600
% White	31.5%	3.9%	32.7%	6.6%	64.2%	10.5%
% Asian	12.9%	1.0%	13.2%	1.7%	26.1%	2.8%
% Black	1.9%	0.1%	1.9%	0.2%	3.8%	0.3%
% Mixed	1.4%	0.0%	1.4%	0.0%	2.9%	0.0%
% Other	1.6%	0.0%	1.4%	0.0%	3.1%	0.1%
Total	49.3%	5.1%	50.7%	8.6%	100.0%	13.7%

Data: ONS mid-2009 ethnic population estimates

Table 3.3: Proportion of Ethnic populations over 60/65 in Leicester, 2009

Ethnic group	% 60/65+ within ethnic group
White	16.4%
Asian	10.6%
Black	8.7%
Mixed	0.0%
Other	2.2%
Total	13.7%

Data: ONS mid-2009 ethnic population estimates

3.5 Ethnicity of people aged over 65 years by ward area

Ward populations by ethnic group are currently only available from the 2001 Census. Leicester has seen large numbers of inward migration from countries such as Poland and Somalia since this Census, however this is unlikely to affect numbers in the over 65s.

The 2001 Census reported the highest number of over 65s from BME groups in Spinney Hills (1,074), Latimer (975), Stoneygate (716), Rushey Mead (618) and Belgrave (595).

Although there are problems projecting the population by minority ethnic group (see Appendix 6), the results of projections conducted for this needs assessment shows a projected overall decline in the numbers in the 'White' and 'Caribbean' groups and substantial increases in all other ethnic groups.

Table 3.4: Population projections by Ethnic group for Leicester residents of all ages

All ages	1991	1996	2001	2006	2011	2016	2021	2026
Leicester	281,450	291,050	282,750	288,500	290,850	293,950	297,600	301,450
White	197,250	191,400	180,400	171,650	162,450	153,450	144,100	134,050
Caribbean	4,750	5,450	4,750	4,700	4,450	4,100	3,900	3,700
African	1,200	1,750	3,700	7,800	12,250	17,750	24,850	33,800
Indian	64,500	72,650	72,500	76,550	77,700	78,650	78,950	78,250
Pakistani	3,000	3,650	4,350	5,550	6,600	7,700	8,850	9,850
Bangladeshi	1,150	1,550	1,900	2,350	2,750	3,150	3,450	3,800
Chinese	1,100	1,350	1,550	1,700	2,050	2,350	2,550	2,700
Other	8,550	13,200	13,550	18,100	22,600	26,800	31,000	35,200
White	197,250	191,400	180,400	171,650	162,450	153,450	144,100	134,050
SA	68,650	77,850	78,750	84,450	87,050	89,500	91,250	91,900
Black	5,950	7,200	8,450	12,500	16,700	21,850	28,750	37,500
Other	9,650	14,550	15,100	19,800	24,650	29,150	33,550	37,900
Total	**281,500**	**291,000**	**282,700**	**288,400**	**290,850**	**293,950**	**297,650**	**301,350**
ONS projections (2006)					**315,500**	**333,300**	**349,400**	**378,600**

Data: Danielis J, Looking at the 'Ethnic Population Forecasts for Leicester using POPGROUP' (a modelling tool)

Table 3.5: Population projections by Ethnic group for Leicester residents 65+ years

Age: 65+	1991	1996	2001	2006	2011	2016	2021	2026
Leicester	42,000	40,800	37,850	36,150	35,600	37,900	40,900	44,700
White	38,300	35,950	31,550	28,250	26,350	26,300	26,150	26,900
Caribbean	300	450	600	800	850	850	850	900
African	0	0	50	100	150	250	400	700
Indian	3,100	3,900	5,000	6,150	7,100	8,950	11,450	13,550
Pakistani	50	100	150	200	250	300	400	500
Bangladeshi	0	50	50	100	150	150	200	250
Chinese	50	50	50	50	50	100	100	150
Other	150	250	400	500	750	1,000	1,350	1,700
White	**38,300**	**35,950**	**31,550**	**28,250**	**26,350**	**26,300**	**26,150**	**26,900**
SA	**3,150**	**4,050**	**5,200**	**6,450**	**7,500**	**9,400**	**12,050**	**14,300**
Black	**300**	**450**	**650**	**900**	**1,000**	**1,100**	**1,250**	**1,600**
Other	**200**	**300**	**450**	**550**	**800**	**1,100**	**1,450**	**1,850**
Total	**41,950**	**40,750**	**37,850**	**36,150**	**35,650**	**37,900**	**40,900**	**44,650**
ONS projections (2006)					**35,700**	**38,700**	**42,400**	**52,300**

Data: Danielis J, Looking at the 'Ethnic Population Forecasts for Leicester using POPGROUP' (a modelling tool)

In the over 65s the biggest increases in numbers between 2011 and 2026 are predicted in the ‘Indian’ category, (which is estimated to almost double), ‘Other’ (more than double), ‘African’ (quadruple) and ‘White’ (2% increase). The projections from the ethnic modelling are lower than the ONS 2006 projections which show a much larger growth rate between 2021 and 2026 whilst the ethnic projections show a much steadier increase over the period.

3.6 Population projections

The overall population of Leicester is predicted to rise by nearly 65,000 over the next 20 years; from around 311,500 in 2010 to 376,000 in 2030. The number of over 65s is estimated to rise by around 2% or nearly 16,000 by 2030.

The largest increases are expected in the 65-69 year olds with an estimated increase of over 5,000. The number of people over 90 is predicted to be more than doubled by 2030 at 3,700. Such increases reveal the great care challenge to Leicester, posed by dementia.

Table 3.6: Projection of population over 65 in Leicester

Age / Year	2010	2015	2020	2025	2030
People aged 65-69	9,400	11,400	12,100	13,300	14,600
People aged 70-74	8,700	8,300	10,100	10,800	11,900
People aged 75-79	6,900	7,300	7,100	8,800	9,400
People aged 80-84	5,400	5,200	5,800	5,800	7,300
People aged 85-89	3,400	3,400	3,600	4,200	4,400
People aged 90+	1,600	2,000	2,400	2,900	3,700
Total 65 +	35,400	37,600	41,100	45,800	51,300
Total Leicester population	311,500	329,800	346,300	361,400	376,000
% of Population 65+	11.4%	11.4%	11.9%	12.7%	13.6%

Data: Projecting Older People Population Information System, www.poppi.org.uk

Table 3.7: Projection of percentage of population over 65 in Leicester

Age / Year	2010	2015	2020	2025	2030
People aged 65-69	3.0%	3.5%	3.5%	3.7%	3.9%
People aged 70-74	2.8%	2.5%	2.9%	3.0%	3.2%
People aged 75-79	2.2%	2.2%	2.1%	2.4%	2.5%
People aged 80-84	1.7%	1.6%	1.7%	1.6%	1.9%
People aged 85-89	1.1%	1.0%	1.0%	1.2%	1.2%
People aged 90+	0.5%	0.6%	0.7%	0.8%	1.0%
Total 65 +	11.4%	11.4%	11.9%	12.7%	13.6%

Data: Projecting Older People Population Information System, www.poppi.org.uk

3.7 Population projections: People living alone and in care homes in Leicester

The impact of dementia is heightened by the increased risk of an older person living alone. The need for well co-ordinated care for people living alone with dementia, to improve their quality of life, avoid premature entry into nursing and residential homes and avoid hospitalisation is a high priority.

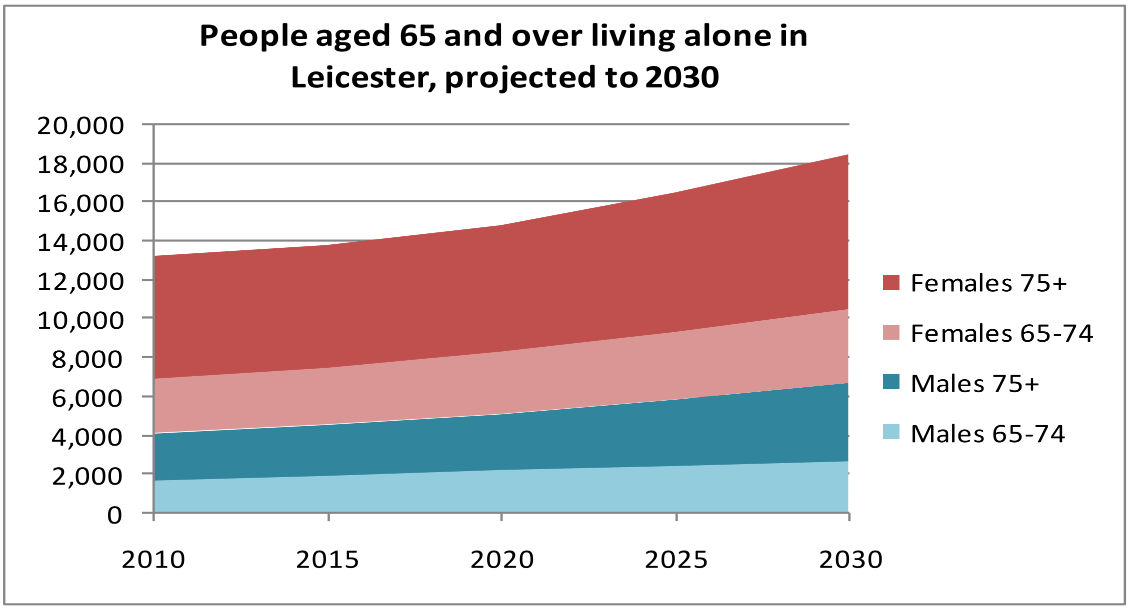
Currently, there over 13,300 people aged 65 and over live alone in Leicester and this is projected to rise to by around 40% to 18,500 by 2030. There are approximately twice as many females aged over 65 than males, and around 1.8 times more people over the age of 75 than aged 65-74 years.

Table 3.8: People aged 65 and over living alone in Leicester

People aged 65 and over living alone in Leicester	2010	2015	2020	2025	2030
Males aged 65-74 predicted to live alone	1,720	1,960	2,260	2,460	2,700
Males aged 75 and over predicted to live alone	2,380	2,584	2,822	3,366	3,978
Females aged 65-74 predicted to live alone	2,850	2,970	3,270	3,540	3,870
Females aged 75 and over predicted to live alone	6,344	6,344	6,527	7,198	7,991
Total population aged 65-74 predicted to live alone	4,570	4,930	5,530	6,000	6,570
Total population aged 75 and over predicted to live alone	8,724	8,928	9,349	10,564	11,969

Data: from www.poppi.org.uk

Figure 4: People aged 65 and over living alone in Leicester

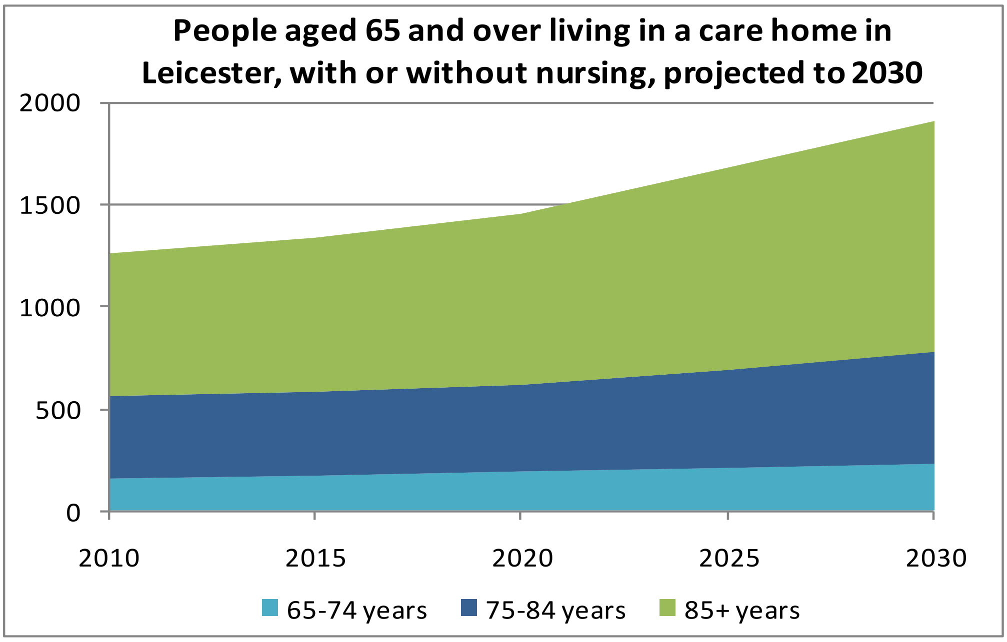


Data: from www.poppi.org.uk

The need for improved care and provision in institutional settings, monitoring psychoactive drug use and improving the quality of life for people with dementia is a present problem which will increase in importance.

The number of people over 65 living in a care home is projected to rise by around 50% from 1,250 (2010) to 1,910 in 2030. The majority of these patients are aged over 85; almost 60% are over 85 years, 28% are in the 75-84 age-group and 12% aged 65-74 years.

Figure 5: People aged 65 and over living in a care home in Leicester



Data: from www.poppi.org.uk

3.8 Population Segmentation

The demographic and lifestyle characteristics of different customer groups can be gained through analysis of market data such as Experian's Mosaic Public Sector. This includes data from a number of sources in order to provide an understanding of peoples' demographics, lifestyles and behaviours. It can be used to anticipate and plan future resource requirements, local area needs and to optimise the allocation of resources. There are 69 Mosaic household types, aggregated into 15 groups to create a classification that can be used at household or postcode level.

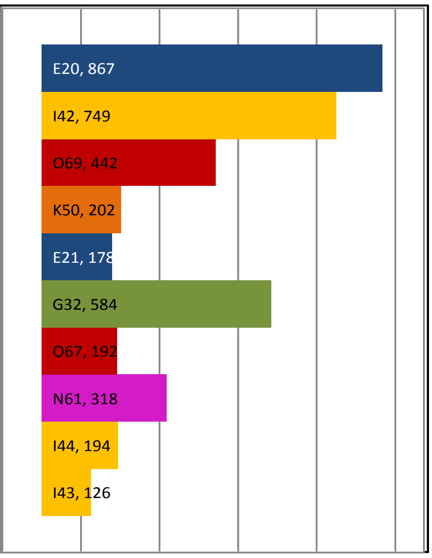
3.8.1 Mosaic groups and types in Leicester

The Mosaic groups found in Leicester are listed in Appendix 10. 22% of Leicester's residents are middle income families compared with 13% in England; 19% are lower income workers compared with only 8% nationally and 15% are families in low rise social housing whilst in England this group represents only 6% of the overall population.

The Lifestyle groups are further sub-divided into Types. The top 2 types within Leicester are 'Upwardly mobile South Asian families' and 'South Asian communities experiencing social deprivation', which together account for nearly a quarter of the population. The third largest group is also a deprived group; 'Vulnerable young parents needing substantial state support'. The top 10 types shown below make up 67% of the population.

Figure 6: Top 10 Mosaic types in Leicester

Mosaic Public Sector Type labels	Leicester	% of Pop	England %	Index
E20 Upwardly mobile South Asian families living in inter war suburbs	45,886	13.0	1.5	867
I42 South Asian communities experiencing social deprivation	37,259	10.5	1.4	749
O69 Vulnerable young parents needing substantial state support	34,512	9.8	2.2	442
K50 Older families in low value housing in traditional industrial areas	23,910	6.8	3.3	202
G32 Students and other transient singles in multi-let houses	20,650	5.8	1.0	584
E21 Middle aged families living in less fashionable inter war suburban semis	18,062	5.1	2.9	178
N61 Childless tenants in social housing flats with modest social needs	15,058	4.3	1.3	318
I44 Low income families occupying poor quality older terraces	14,806	4.2	2.2	194
O67 Older tenants on low rise social housing estates where jobs are scarce	14,396	4.1	2.1	192
I43 Older town centres terraces with transient, single populations	12,097	3.4	2.7	126



3.8.2 Mosaic profile of over 65s in Leicester

The Mosaic Groups and Types reflect the most common household type within the 15 households of each postcode. Based on the postcodes of Leicester residents, the most common 3 groups in those aged over 65 are also the most common 3 groups for all ages of Leicester residents although the proportions vary slightly. The top 3 groups account for 50% of all the over 65s in Leicester and the top 10 groups account for 93% of all over 65 year olds.

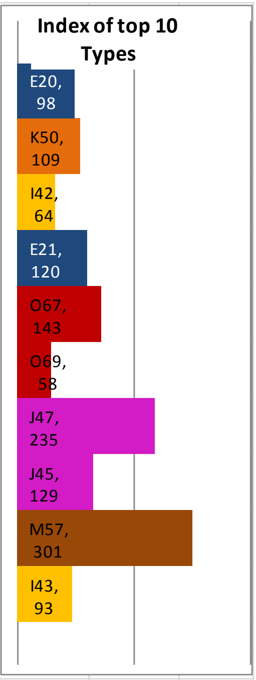
The most common Mosaic Type in the over 65s is 'Upwardly mobile South Asian families' who represent similar proportions as in the whole population (13%). However, the number of over 65s in the group 'South Asian communities experiencing social deprivation' have much lower representation (6.7%) than in all residents (10.5%). The second most common type for over 65s is 'Older families in low value housing' (7.3%).

The chart shows the index of types that are over represented in the over 65s compared with the population of all ages in Leicester. There are over 3 times more 'Old people in flats subsisting on welfare payments', 2.3 times more 'Comfortably off industrial workers owning their own homes' and 1.4 times as many 'Older tenants on low rise social housing estates where jobs are scarce'.

Mosaic Group data confirms that the over 65s generally live towards the outskirts of the city, with very few in the City Centre and Knighton. Of the larger Mosaic groups, ***upwardly mobile South Asian families*** are found mainly in eastern Leicester, in Latimer and Stoneygate wards, with smaller numbers in Spinney Hills, Belgrave and Rushey Mead. The group ***South Asian communities experiencing social deprivation*** are also found in Spinney Hills ward with some cases in Charnwood and Stoneygate. The group, o***lder families in low value housing*** are found in Eyres Monsell with some in Braunstone and Thurncourt.

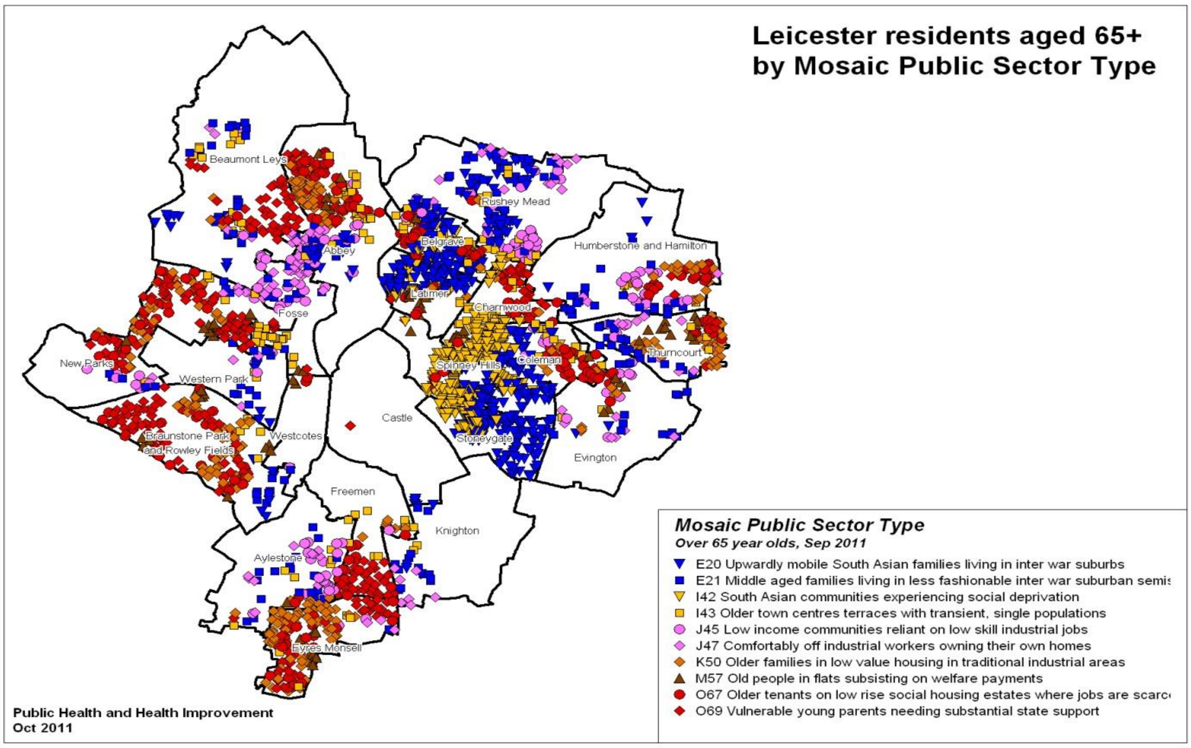
Figure 7: Over 65s in Leicester by top 10 Mosaic Types, compared with Leicester overall

Mosaic Public Sector Type	Leicester Pop aged 65+ years	% of Over 65s	Leicester %	Index
E20 Upwardly mobile South Asian families living in inter war suburbs	4,951	12.8	13.0	98
K50 Older families in low value housing in traditional industrial areas	2,847	7.3	6.8	109
I42 South Asian communities experiencing social deprivation	2,610	6.7	10.5	64
E21 Middle aged families living in less fashionable inter war suburban semis	2,386	6.1	5.1	120
O67 Older tenants on low rise social housing estates where jobs are scarce	2,265	5.8	4.1	143
O69 Vulnerable young parents needing substantial state support	2,190	5.6	9.8	58
J47 Comfortably off industrial workers owning their own homes	1,672	4.3	1.8	235
J45 Low income communities reliant on low skill industrial jobs	1,372	3.5	2.7	129
M57 Old people in flats subsisting on welfare payments	1,293	3.3	1.1	301
I43 Older town centres terraces with transient, single populations	1,231	3.2	3.4	93
Total	**38,808**	**58.8**	**58.3**	



Data: GP Patient Lists, Experian Mosaic groups

Figure 8: Over 65s in Leicester by top 10 Mosaic Types

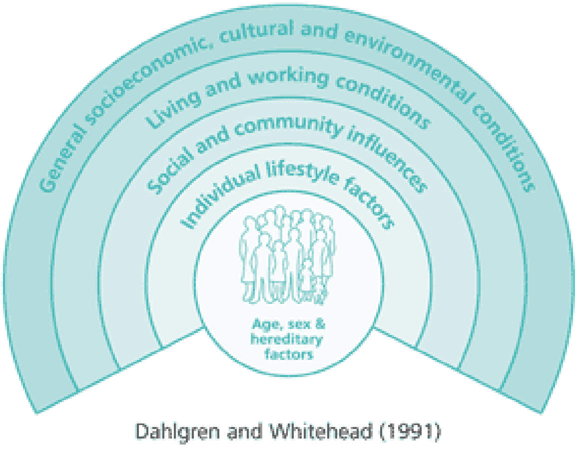


Data: GP Patient Lists, Experian Mosaic groups

3.9 Index of multiple deprivation

Quality of life and well being involve more than the absence of illness and disability. They are influenced by an individual's physical and social environment, and their perception of their environment. Poor health and well being is both a contributor to and a consequence of wider health inequality[51]. The *Independent Inquiry into Health Inequalities report*[52] adopted a socio-economic model of health in line with the weight of scientific evidence. This model is shown in Figure 6, below.

Figure 9: Socio-economic model of influences on health



The model shows the main determinants of health which have a cumulative effect on health and wellbeing. At the centre are factors which cannot be altered, such as gender and genetic factors. Surrounding the centre are factors which can be modified. The first layer represents personal behaviour and individual lifestyle, which comprises factors that have the potential to promote or damage health, such as smoking and physical activity. The second layer is made up of social and community factors, in effect the impact of social interaction on sustaining health and the adverse effect of isolation. Layer three includes living and working conditions and the outer layer represents economic, cultural and environmental conditions prevalent in society as a whole.

Deprivation in Leicester is high and although there are some pockets of wealth, the majority of city areas experience extreme deprivation. The Index of Deprivation 2010[53] is a measure of poverty based on a number of criteria such as economic circumstances, health, crime, housing, educational achievement, skills and the environment. This measure ranks Leicester as the 25th most deprived of 326 Local Authority areas.

Over 40% of Leicester's population live in the fifth (0-20%) most deprived areas nationally and a further 33% live in the 20-40% most deprived areas. Of these, 12% of Leicester's population live in extreme poverty; over 36,000 people live in the 5% most deprived areas in England. Less than 1.5% of Leicester's population live in the fifth least deprived of areas nationally.

Table 3.9: Leicester's population by quintile of deprivation

Quintile of deprivation	Population	% Population
Q1 (0-20%)	124,467	40.6%
Q2 (20-40%)	103,155	33.6%
Q3 (40-60%)	52,033	17.0%
Q4 (60-80%)	22,796	7.4%
Q5 (80-100%)	4,180	1.4%
Total	**306,631**	**100.0%**

Data: Index of Deprivation 2010, ONS mid-2010 population estimates

There are similar proportions of Leicester's population aged over 65 living in areas of deprivation.

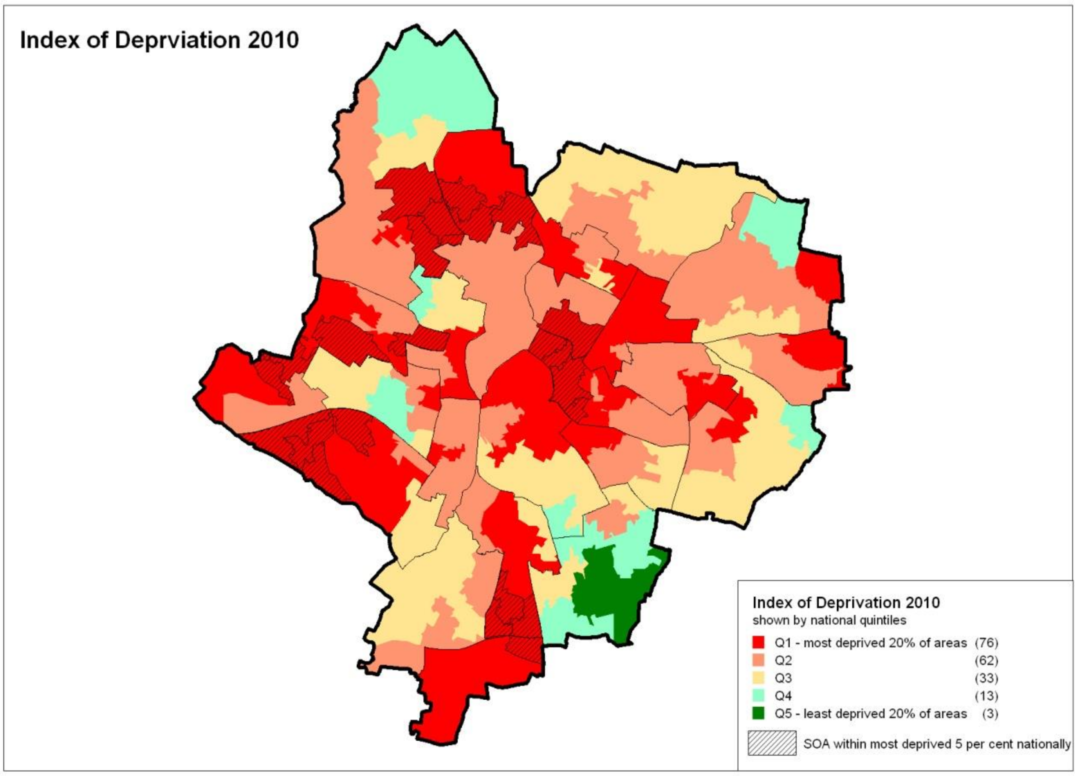
Table 3.10: Leicester's population 65+ by quintile of deprivation

Quintile of deprivation	Population 65+	Over 65s as % all Over 65s	Over 65s as % total population
Q1 (0-20%)	13,361	37.5%	4.4%
Q2 (20-40%)	11,277	31.6%	3.7%
Q3 (40-60%)	7,479	21.0%	2.4%
Q4 (60-80%)	2,854	8.0%	0.9%
Q5 (80-100%)	668	1.9%	0.2%
Total	**35,639**	**100.0%**	**11.6%**

Additionally, Leicester has two lower super output areas (an LSOA has around 1,500 people) which rank 1st and 2nd for the most deprived areas in England overall for Education, Skills and Training. There are also two LSOAs ranking 2nd and 6th for the most deprived areas for Income nationally.

The index of deprivation 2010 has a supplementary index showing income deprivation affecting older people, expressed as the proportion of adults aged 60 or over living in Income Support, income-based Jobseeker's Allowance or Pension Credit (Guarantee) families.

Figure 10: Index of deprivation (2010) in Leicester



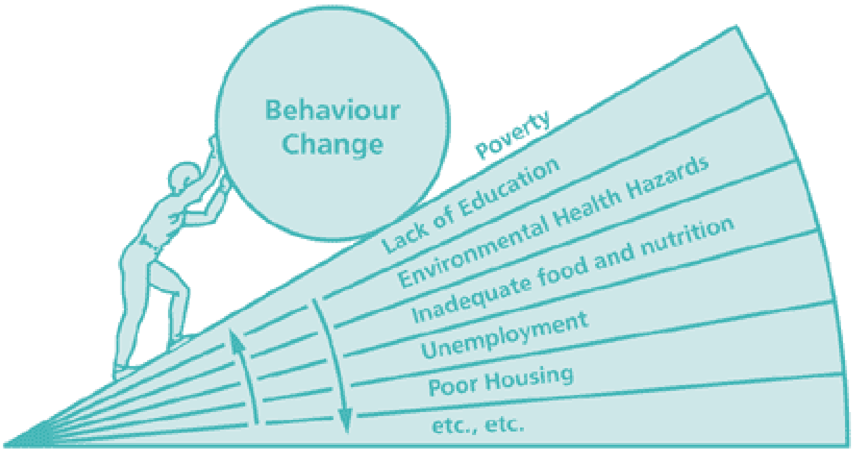
3.10 Indices of multiple deprivation as they affect older people

Many influences on health are underpinned by a social gradient, with conditions conducive to health becoming less favourable with declining social status. People from more deprived quintiles have a greater exposure to health hazards and risk factors, resulting in health inequalities. The *Annual Report of the Director of Public Health for Leicestershire 2001*[54]used a diagram (Figure 8 below) to show how promoting healthy lifestyles for people in disadvantaged circumstances is unlikely to be effective without appropriate support and structural changes. Marmot et al[55] suggested that the impact of this social gradient is such that better a social and economic position results in better health. One explanation for this is that relative deprivation may provoke negative emotional and cognitive responses to inequity[56].

The *Social Exclusion of Older People: Evidence from the first wave of the English Longitudinal Study of Ageing (ELSA)*[57] suggests that there are seven key characteristics that are most strongly related to an older person experiencing multiple exclusions:

- Age: being 80 and over;
- Family type: living alone, having no living children;
- Health: poor mental or physical health;
- Mobility: no access to private car and never uses public transport;
- Housing tenure: rented accommodation;
- Income: low income, benefits as the main source of income
- Telephone: those without access to a telephone.

Figure 11: Barriers to behaviour change based on socio-economic model (LHA, 2001)



Quality of life and well being of older people is a theme in the report *From welfare to Wellbeing*[58] which proposed a shift in the way that society and government address the aging population in order to tackle age discrimination and inequality. This report found that public services generally focus on the most vulnerable older people only at times of crisis rather than adopting an approach which would enable the wider older population to remain independent for as long as possible and live their lives to the full. It found that many older people are excluded from universal services.

Many older people are carers, according to the 2001 Census 5.2 million people in England and Wales did some caring and over 1 million people provided more than 50 hours a week of caring. More than half of these were over the age of 55 and many reported themselves as not in good health. Approximately 20% of people over the age of 50 provide unpaid care. The majority of carers under the age of 65 are female; those aged 65 and over are more likely to be male[59].

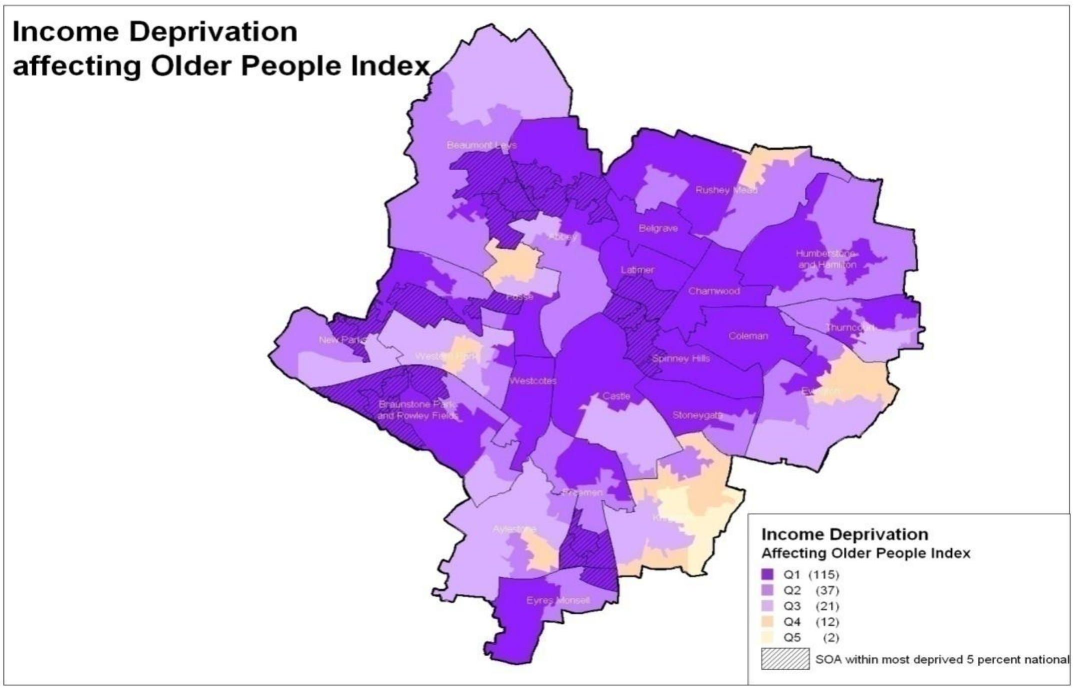
One aspect of material well being which is pertinent to older people is the issue of fuel poverty, a financial position where a household needs to spend more than 10% of its income on fuel in order to provide an adequate standard of warmth. Older people are at risk of fuel poverty because they rely on pensions, which provide an income which is lower than the general population. The impact on a person's health can be great; for instance the cost of fuel may cause people to have poor nutrition, either to eat or heat[60]. The health of older people is more affected by cold stress[61], the have a greater fall in core body temperature in response to the cold, and are more affected by excess winter mortality.

Housing is can also be problematic for older people, not just in relation to adequate heating, but also with regard to safety, access to disabled facilities. The report *Delivering Housing to an Ageing Population*[62] suggested that older people want to live in their own homes, their local area and be involved in the local community for as long as possible. However, many old people live in poor quality accommodation, many have difficulties with mobility in the home, and older people fear falling in the home and have difficulty accessing adaptations and local amenities.

Social exclusion of older people may also be affected by transport or the fear of crime. With regard to transport, older people are more dependent on public transport and are more likely to have problems accessing local amenities. According to *Excluded Older People*[63] transport issues are problematic for older people. A *Sure Start to later life*[64] also suggested that poor transport, limited mobility and lack of services contribute to social exclusion. Fear of crime can have adverse effects on the lives of older people, reducing social contacts and their sense of well being. Evidence provided by Age Concern suggests that 25% of older people felt that [65] street crime was a problem in their area and that 72% believed that a person is more likely to experience crime as they get older.

Figure 10 below shows that Areas of high income deprivation are generally the same as areas of high multiple deprivation. However, there are areas in eastern Leicester (Rushey Mead, Belgrave, Latimer, Coleman, and Spinney Hills) which fall into the worst quintile nationally for Income deprivation affecting older people where they are in quintile 2 for the index of multiple deprivation.

Figure 12: Income deprivation affecting older people (2010)



Data: Idex of deprivation 2010

4. Prevalence of dementia in Leicester

The *Dementia UK* report[66] used the Expert Delphi Consensus to produce estimates of the prevalence of dementia. It suggests that there are around 684,000 people with dementia in the UK, with around 574,000 (84%) resident in England. This corresponds to a prevalence of dementia for the population of England of 1.1%. Currently a large proportion of these people are likely to be undiagnosed.

The report also used the advice of UK and European experts to produce a consensus that:

- The prevalence of both early onset and late onset dementia increases with age, doubling with every five-year increase across the entire age range from 30 to 95-and-over.
- The prevalence of early onset dementia is higher in males than females for those aged 50–65, whilst late onset dementia is marginally more prevalent in females than males.
- Alzheimer’s disease is the dominant subtype of dementia, particularly among older people and in women.
- Frontotemporal dementia was considered to account for a substantial proportion of early onset cases among younger men.
- The report estimates that there are 11,392 people from Black and minority ethnic (BME) groups with dementia in the UK.
- There is a greater rate of early onset of dementia amongst people from BME groups (6.1% against 2.2% for the UK population as whole.
- The prevalence of dementia among people in institutions varied little by age or gender, increasing from 55.6% among those aged 65–69 to 64.8% in those aged 95 and over.

The consensus group advising *Dementia UK* also estimated that the prevalence of dementia among all those aged 65 years and over living in elderly mentally infirm homes was 79.9%, in nursing homes it was 66.9% and 52.2% in residential care homes.

With regard to deaths which are attributable to dementia, the report found that mortality attributable to dementia increases from 2% at age 65 to 18% at age 85–89 in males, and from 1% at age 65 to a peak of 23% at age 85–89 in females. Overall, 10% of deaths in men over 65 years, and 15% of deaths in women over 65 years are attributable to dementia. Annually, 59,685 deaths among the over 65s could have been averted if dementia were not present in the population. The majority of these deaths occurred among those aged 80–95 years. Delaying the onset of dementia by five years would halve the number of UK deaths due to dementia to 30,000 a year[67].

Launer et al[68] reviewed the estimates of the incidence of all dementia and Alzheimer’s disease derived from four European studies. They give the incidence rate for dementia as 2.5 per 1000 person-years (95% CI: 1.6–4.1) at age 65, rising to 85.6 (95% CI: 70.4–104) at age 90. These rates are inclusive of mild dementia.

4.1 Prevalence of dementia

This section presents information on the estimated prevalence of dementia in Leicester. This has been estimated by applying prevalence estimates for the UK[69] to Leicester's population.

Prevalence of late-onset dementia in the UK is relatively low in 65-69 year olds (1.3%), increasing with age to almost a third of the population aged 95 and over. The prevalence is slightly higher in females compared to males. In Leicester this would equate to around 1,690 females and 920 males aged 65 and over.

Table 4.1: Prevalence of late-onset dementia in the UK

	Prevalence			Estimated number in Leicester		
Age (years)	**F %**	**M %**	**Total %**	**F**	**M**	**Total**
65-69	1	1.5	1.3	*49*	*68*	*123*
70-74	2.4	3.1	2.9	*113*	*125*	*253*
75-79	6.5	5.1	5.9	*251*	*157*	*409*
80-84	13.3	10.2	12.2	*427*	*226*	*662*
85-89	22.2	16.7	20.3	*486*	*203*	*691*
90-94	29.6	27.5	28.6	*262*	*115*	*373*
95+	34.4	30	32.5	*103*	*28*	*128*
Total				**1690**	**922**	**2639**

Data: based on Alzheimer's Society. Dementia UK. The full report, 2007 applied to Leicester population

In people aged below 65 years dementia is much less common, affecting less than 1% of the population or around 70 people, in Leicester.

Table 4.2: Prevalence of early-onset dementia in the UK

	Prevalence per 100,000			Estimated number in Leicester		
Age (years)	**F**	**M**	**Total**	**F**	**M**	**Total**
30-34	9.5	8.9	9.4	*1*	*1*	*2*
35-39	9.3	6.3	7.7	*1*	*1*	*2*
40-44	19.6	8.1	14	*2*	*1*	*3*
45-49	27.3	31.8	30.4	*3*	*3*	*6*
50-54	55.1	62.7	58.3	*5*	*5*	*10*
55-59	97.1	179.5	136.8	*7*	*14*	*21*
60-64	118	198.9	155.7	*8*	*13*	*20*
45-64	**66.2**	**99.5**	**84.7**	**28**	**43**	**72**

Data: based on Alzheimer's Society. Dementia UK. The full report, 2007 applied to Leicester population

According to Dementia UK there were 1,436 people on general practice registers in Leicester with a diagnosis of dementia. This number is lower than expected when the national prevalence rate is applied to the Leicester population. The actual number of people with dementia is estimated to be 3,191 people (Table 4.3).

Table 4.3: Prevalence of diagnosed and undiagnosed dementia in the UK

	Prevalence		Estimated number in Leicester		
Age (years)	F %	M %	F	M	Total
30-59	0.09	0.16	*51*	*94*	*145*
60-64	0.47	1.58	*30*	*103*	*133*
65-69	1.1	2.17	*54*	*99*	*152*
70-74	3.86	4.61	*182*	*186*	*368*
75-79	6.67	5.04	*258*	*155*	*413*
80-84	13.5	12.12	*433*	*269*	*702*
85-89	22.76	18.45	*498*	*224*	*722*
90-94	32.25	32.1	*285*	*134*	*420*
95+	36	31.58	*108*	*29*	*137*
Total			1898	1293	3191

Data: Dementia 2010

4.2 Incidence of dementia

Prevalence relates to the total number of people with dementia at any one time. Incidence shows the number of new cases. Applying the national incidence rates to Leicester's population gives an estimated 730 new cases of dementia each year.

Table 4.4: Incidence of late onset of dementia (per 1,000) in England and Wales

	Rate per 100,000		*Estimated number in Leicester*		
Age (years)	F	M	*F*	*M*	*Total*
65-69	6.3	6.9	*31*	*31*	*62*
70-74	6.1	14.5	*29*	*58*	*87*
75-79	14.8	14.2	*57*	*44*	*101*
80-84	31.2	17.0	*100*	*38*	*138*
85+	71.7	58.4	*242*	*101*	*343*
Total			459	272	731

Data: based on Medical Research Council Cognitive function and Ageing Study, 2005 applied to Leicester population

4.3 Types of dementia

Prevalence of different types of dementia varies between men and women and by age group. The figure below shows a summary of the overall proportions of types of dementia and the estimated numbers by applying these figures to the population of Leicester with dementia. Alzheimer's disease is the most common type, accounting for over 60% of dementias, with vascular dementia the next common accounting for 17%. A mix of Alzheimer's disease and Vascular Dementia accounts for 10% of cases.

Table 4.5: Proportion of people with dementia by type

Age (years)	Proportion of people with dementia (%)	*Estimated number in Leicester*
Alzheimer's disease	62.0	*1681*
Vascular dementia	17.0	*461*
Mixed (AD and VD)	10.0	*271*
Dementia with Lewy bodies	4.0	*108*
Frontotemporal dementia	2.0	*54*
Parkinsons' dementia	2.0	*54*
Other	3.0	*81*
Total	100.0	*2711*

Data: based on Alzheimer's Society. Dementia UK. The full report, 2007applied to Leicester population

4.4 Severity of dementia

This needs assessment has shown that one way of classifying dementia is by the headings mild, moderate of severe. The majority of the population has mild dementia (around 55%), 32% have moderate dementia and 13% severe dementia. As dementia is progressive, the proportion of people with severe dementia increases as people grow older; from around 6% in 65-69 year olds to 23% in 95 years and over. When these are applied to the Leicester population, there are 1,456 people with mild dementia, 850 with moderate and over 300 with severe dementia.

Table 4.6: Proportion of people with mild, moderate and severe late onset of dementia applied to the Leicester population

	% with dementia			*Estimated number in Leicester*		
Age (years)	Mild	Moderate	Severe	*Mild*	*Moderate*	*Severe*
65-69	62%	32%	6%	*76*	*39*	*7*
70-74	63%	30%	7%	*160*	*76*	*18*
75-79	57%	31%	12%	*233*	*127*	*49*
80-84	57%	32%	11%	*377*	*212*	*73*
85-89	54%	33%	13%	*373*	*228*	*90*
90-94	49%	33%	18%	*183*	*123*	*67*
95+	42%	35%	23%	*54*	*45*	*29*
Total				***1456***	***850***	***333***

Data: based on Alzheimer's Society. Dementia UK. The full report, 2007

4.5 Residential status

People with dementia will need different levels of care, depending on their age and severity of the disease. Estimates show around 73% of people aged less than 85 years with late-onset dementia live in the community (either in their own homes or with family/others) and around 27% live in a care home. This proportion increases with age, with over 60% of those with dementia aged over 90 living in care homes.

Table 4.7: Proportion of people with late onset dementia living at home and in care homes

Age (years)	% living in community	% living in care homes	*Estimated number in Leicester* *Living in community*	*Living in care homes*
65-74	73.4%	26.6%	*276*	*100*
75-84	72.2%	27.8%	*774*	*298*
85-89	59.1%	40.9%	*408*	*283*
90+	39.2%	60.8%	*196*	*304*
Total			*1654*	*985*

Data: based on Alzheimer's Society. Dementia UK. The full report, 2007 applied to Leicester population

5. Mortality from Dementia

5.1 Deaths attributable to dementia

Dementia shortens the lives of those who develop the condition; the mean survival with Alzheimer's is estimated at approximately 7.1 years and 3.9 years for vascular dementia[70]. People with dementia often have other health conditions so it is difficult to assess the contribution of dementia to the cause of death. A population attributable risk fraction has been developed based on empirical evidence (age, sex, death certificates acknowledging dementia) to show the theoretical contribution of dementia to cause of death.

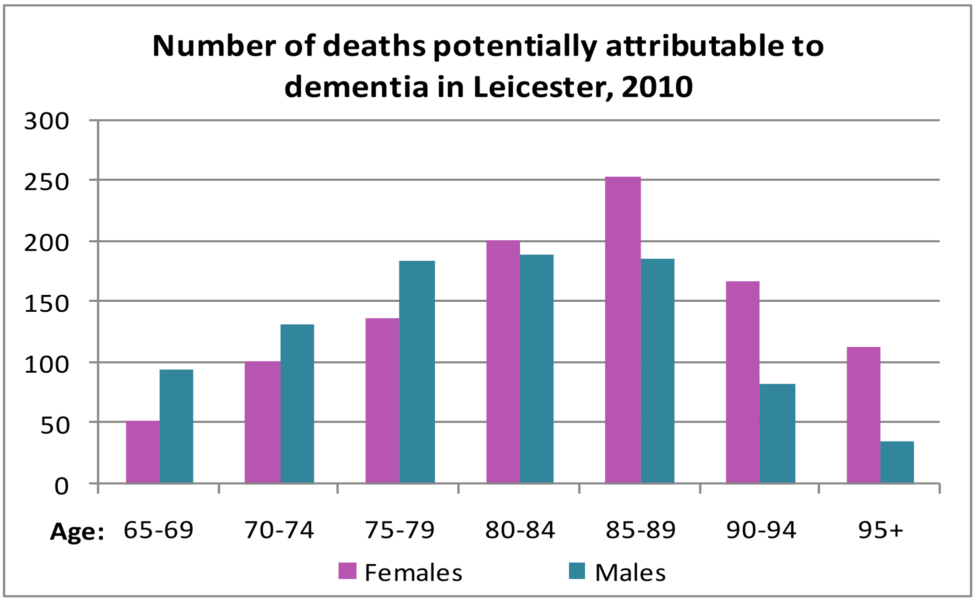
Table 5.1: Proportion of deaths theoretically attributable to dementia, 2010

Age group	Females AF	Males AF	Female Deaths	Male Deaths	Female dementia deaths	Male dementia deaths	All
65-69	1%	2%	52	95	0.52	1.9	2.42
70-74	3%	3%	102	133	3.06	3.99	7.05
75-79	8%	7%	138	184	11.04	12.88	23.92
80-84	15%	12%	201	190	30.15	22.8	52.95
85-89	23%	18%	255	186	58.65	33.48	92.13
90-94	19%	14%	167	83	31.73	11.62	43.35
95+	21%	15%	113	35	23.73	5.25	28.98
All	15%	10%	1028	906	158.88	91.92	250.8

Data: based on Dementia UK, The Full Report 2007 Attributable fractions for dementia applied to Leicester deaths for 2010

Overall, around 10% of deaths in men and 15% of deaths in women are attributable to dementia. The proportion of deaths attributable to dementia increases from age 65 (1% in men, 2% in women) to a peak at 85-89 years (18% in men and 23% in women). These fractions have been applied to deaths in Leicester:

Figure 13: Number of deaths potentially attributable to dementia in Leicester, 2010



Data: based on Dementia UK, The Full Report 2007 Attributable fractions for dementia applied to Leicester deaths for 2010

If dementia could be removed from the population, around 250 deaths per year in the over 65s in Leicester would be averted. If the onset of dementia could be delayed by around 5 years, by a combination of public health improvement (cardiovascular risk factor reduction and diet) and preventative treatments, this could halve the prevalence of dementia in each 5 year age band and theoretically also halve the number of deaths attributable to dementia.

6. The role of primary health care

6.1 General practice and early diagnosis

One of the main issues for people with dementia and their carers is the availability of an early and accurate diagnosis. If a person with dementia is diagnosed early it enables them and their family and carers to engage with support services, plan for the future; an early diagnosis can reduce psychological distress[71]. For Briggs[72] an early diagnosis can enable people to access knowledge about medical, psychological and social support which could improve morale, lessen carer stress and reduce admission to care homes[73].

However, evidence suggests that the majority of GPs feel inadequately trained in the diagnosis and management of dementia[74]. They also feel that they have little to offer people with dementia[75], and find explaining the diagnosis of dementia particularly difficult[76]. Many GP's find that patients do not want the stigma of a label of dementia; in response GPs are more likely to utilise vague symptomatic terms, such as 'mild memory problems', to describe early dementia.

Studies of relatives of people with dementia also suggest that, from their perspective, physicians are reluctant to make a diagnosis[77] [78]. In consequence, less than two thirds of GPs felt that it was actively important to look for symptoms. The National Audit Office (NAO) report, *Improving services and support for people with dementia*[79] found that GPs' attitudes could hamper early diagnosis, that there was a common perception among GPs that little could be done for a person with dementia even if the illness was diagnosed early. It also found that GPs' confidence in diagnosing dementia had fallen in the period since 2004. Only 31% felt that they had enough training to diagnose and manage the disease and 70% felt that they had too little time to spend on people with dementia[80].

Similar findings were described in the Audit Commission report, *Forget Me Not*[81]. This showed that 40% of GPs are reluctant to diagnose dementia early, the majority of GPs do not use protocols to help diagnose dementia, and that fewer than 50% of GPs felt that they had sufficient training for the diagnosis and treatment of people with dementia.

To some extent the a lack of urgency attached to diagnosing and addressing the disease may explain why, despite the apparent benefits of early diagnosis, the numbers of people who are diagnosed are lower than the estimated prevalence; in effect a diagnosis gap.

6.2 Cases of dementia on GP registers in Leicester

In 2011 there were 1,436 people in Leicester registered as having dementia, whilst the estimated prevalence of dementia in suggested that there are 2639 people with the disease. Table 9.1 shows that this means that 54.4% of the population estimated to have dementia have been diagnosed. In many respects this diagnosis gap confirms that Leicester is no different to the rest of the UK. However, the gap between reported and estimated prevalence in Leicester has reduced since 2010, when there were an estimated 2,606 people with dementia in Leicester of whom only 1,100 were on GP registers (42.2% of the estimated total)[82]. The likelihood is, though, that GPs may be more aware of potential cases of dementia than the formal QOF registers indicate, and they could be more involved in early diagnosis.

Table 6.1: Numbers of people with dementia in Leicester projections and proportions on the dementia register (Source, *Dementia UK* (2007) [83]

Primary Care Trust Area	Estimated number of people with dementia in 2011	Estimated number of people with dementia in 2021	% Projected increase in number of people with dementia by 2021	Numbers of people on a GP register April 2007-March 2008	% of the numbers of people with dementia on the register
Leicester City	2639	3023	14.5	1436	54.4

Table 6.2 shows the 2011 Leicester QOF register data by GP locality. The expected number of people with dementia is greatest for Leicester City Central, with 1,046 cases expected from a list size of 120,839. The greatest expected prevalence is 1.3% for the NEL Cluster; the age profile of this locality is older than the other localities.

Table 6.2: QOF expected and actual prevalence of dementia by GP locality 2011

Locality	Dementia Register	Listsize	QOF Prevalence 2011	Expected Number with dementia*	Expected prevalence	% Diagnosed
Leicester Primary Care Group	481	108563	0.4%	832	0.8%	57.8%
Leicester City Central	306	120839	0.3%	1046	0.9%	29.2%
Millennium Health	277	78864	0.4%	728	0.9%	38.1%
NEL cluster	372	56822	0.7%	749	1.3%	49.7%
Leicester Total	**955**	**366135**	**0.3%**	**2523**	**0.7%**	**37.8%**

With regard to actual QOF registrations, Leicester Primary Care Group had 481 of 832 expected cases of dementia registered (57.8%); NEL Cluster have 372 cases of dementia registered, out of an estimated 749 (49.7%); Millennium Health had 277 registered from an estimated 728 cases (38.1%); Leicester City Central had 306 registered from an estimated 1,246 cases (29.2%). Whilst the numbers of cases diagnosed and registered has improved since 2011, this data suggests that particular activity could be focused on Leicester City Central.

Recommendation: To note the observed and expected rate of dementia by general practice locality.

6.3 General practice role in improving diagnosis of dementia

To improve rates of early diagnosis, there is a need for GPs to conduct cognitive tests, such as ADAS-Cog or Mini Mental State Examination, to assess patients in periods of watchful waiting and to make referrals to the Memory Assessment Service. Such tests can be used to assess a number of different mental abilities including short and long-term memory, attention span, language and communication skills, and ability to plan and to understand instructions. Whilst the results of such assessments may be confounded by factors, such as by a person's educational background they are recognised as being of value in providing a baseline, and the MMSE is also recommended by NICE[84] when deciding whether a drug treatment for Alzheimer's disease should be prescribed.

There are other tests involved in the diagnosis of dementia, for example a range of blood tests to rule out other possible causes of symptoms, such as a vitamin B deficiency or syphilis, and a review of medication, which may have been contributing to a person's symptoms. Such tests may also help to differentiate between the different types of dementia. Referral to specialists should be focussed upon cases such as determining the presence of dementia as opposed to MCI and normal ageing; in effect determining a person who comes under Care Cluster 18.

GPs can also be involved in the diagnosis of dementia in those cases which do not require specialist input for diagnosis. This would include those cases of people with moderate or severe dementia who have not been diagnosed. Many such cases may be more straightforward to diagnose, in particular those people whose condition has deteriorated, who are labelled as confused and who have already become progressively dependent. These cases come under Care Clusters 19 and 20.

Recommendation: A primary care model should be developed to for GPs to be involved in early diagnosis of people with dementia, using a cognitive assessment tool, watchful waiting of potential cases, referral for blood tests and brain scans, and referral to the Memory Assessment Service.

This recommendation links to Strategic Priority 1 of the local dementia commissioning strategy and to objective 2 of the national dementia strategy.

In order to facilitate greater involvement of primary care in the diagnosis and treatment of people with dementia there should be shared care arrangements between primary care and secondary care providers (currently Leicestershire Partnership Trust). Given the changes to the technical appraisal on medications for Alzheimer's disease, the loss of patent protection for donepezil and the use of memantine as a first line treatment for moderate to severe Alzheimer's disease, shared care arrangements are immediately necessary.

Such agreements should enable secondary care to focus on those people requiring complex early diagnosis or complex treatment. The agreements should also ensure that there is increased access to appropriate treatment. There are a number of service providers which could be used to deliver this service but, given possible lack of capacity in general practice, the best option is most likely to be a separate provider working closely with local practices and social care.

Recommendation: There should be shared care arrangements between primary and secondary care to enable people with dementia to have access to appropriate care; including medications and support with activities of living.

The NICE quality standards also suggest that early diagnosis will allow patients and carers to receive information about their condition and local support options. It will also allow people with dementia to have ongoing care planned and evaluated. QMAS data records the number of people with dementia whose care had been reviewed in the previous 15 months. This data shows that in January 2011 821 of the 1380 people registered with dementia in Leicester (59.5%) had their care reviewed in the preceding 15 months. In effect, only 31% of the population who are expected to have dementia have had a review of their care in the previous 15 months.

Table 6.3: Numbers of people registered with dementia in Leicester who have had a review in the last 15 months (Source, QMAS Data Jan 2011)

Primary Care Trust Area	Numbers of people on a GP register Jan 2011	Numbers of people on a GP register reviewed in previous 15 months	% patients diagnosed with dementia whose care has been reviewed in the previous 15 months
Leicester City	1380	821	59.5

Recommendation: There should be an improvement in the number of people with dementia who have been reviewed by their GP in the previous 15 months.

6.4 Primary care support for carers

Given the detrimental impact of caring on a person's mental health and wellbeing, primary care support for carers of people with dementia is also essential. General practice can be decisive in assessing the capacity of a carer to cope, assessing the health and wellbeing of those family members contributing to care and ensuring that they have information about the services and benefits which are available to them[85].

One of the main areas which may benefit cares, and which could be offered in primary care, is flexibility. The recognition that caring is difficult and not straightforward. For example, that sometimes aspects of daily routine, such as getting out of the house or waiting in busy reception areas, are difficult for carers and the care recipient. In response to this primary care should offer greater flexibility for carers. In order to raise awareness that everyone has a role in dementia care local work stream 5 is involved in developing a workforce which is fit for purpose, reviewing the feasibility of offering training courses aimed at different levels.

Recommendation: GPs should better identify and meet the needs of carers. In order to facilitate this they should keep up to date QOF registers of carers or there should be strict monitoring of current QOF requirements for the care of patients with dementia.

Recommendation: All primary care staff should have training about the needs of people with dementia and their carers appropriate to their role in the Dementia Care Pathway.

As part of the QOF for dementia, there is an obligation to consider carers' needs. In addition there is potential for a separate carers' register to be held by each general practice as part of the quality and outcomes framework. This should be used to facilitate the offer of an annual health check for carers of people with dementia.

Recommendation: All carers should be invited for an optional annual health check.

6.5 The wider primary care team

Although GPs are the leaders of primary health care teams, these teams comprise a wide range of roles. In primary care people with dementia are more likely to be in the care of Community Mental Health Teams, although GPs, district nurses, community matrons and community psychiatric nurses (CPNs) may be involved at some point during the care pathway. Supporting people at home, with regular home visits may provide the best means of reviewing each case, encouraging caregivers and monitoring the need for further action. CPNs are often engaged in such care; Hughes and Summerfield found that about 60% of the CPN caseload was involved in caring for older patients[86].

Once a diagnosis is in place, or when the person's condition deteriorates a package of care may be needed with contributions from a number of services. Patients who have co-existing medical or surgical conditions may require access to a wide range of services, which are often accessed through primary care. For example, an older person with dementia and a fractured neck of femur may need orthopaedic surgery, geriatric assessment, liaison psychiatry and the support of rehabilitation services. Eventually there may be a need for long term residential or nursing care.

This will demand the involvement of services covering primary, secondary and social care. Effective co-ordination of specialist medical, general medical, community nursing and social welfare services is therefore a prerequisite of dementia care, and the contribution of primary health care teams is a major component of this care provision. It will also require that the workforce is developed so that the members have confidence in adapting their actions and communication in order to respond appropriately to people with dementia and their carers. The training that the workforce receives should be based on the common core principles for supporting people with dementia[87] (See Appendix 12), or training which reflects their role in the wider team.

Recommendation: Members of the primary care team, including reception staff, should receive appropriate training to respond appropriately to people with dementia and their carers.

7. Memory Assessment Service

7.1 Memory Clinics

A diagnosis of dementia is often made at a memory clinic, although it is important to add that not all people attending a memory assessment service will have dementia. Some people who have been referred to a memory clinic may have cognitive impairment that does not meet the criteria for dementia[88]. But memory assessment clinics require consideration because they are significant participants in early diagnosis.

Memory clinics emerged in the USA in the 1970s, and were principally aimed at identifying people in the early stages of dementia. Since 1983 there has been a similar development in the UK. Wright and Lindesay[89] identified 20 memory clinics in the Britain and Ireland (14 in England, two in Wales, three in Scotland and one in the Irish Republic). Of these clinics 12 had started within the preceding three years. Most patients were referred by physicians (GPs, psychiatrists or geriatricians), but some clinics accepted family or self-referrals, and nearly all took patients from outside their own areas. All provided a multi-disciplinary assessment (psychiatric, psychological and geriatric) and most shared a common core of tests and investigations (physical examination; MMSE; full blood count; urea and electrolytes; thyroid and liver function tests; vitamin B12 and folate levels; serum glucose).

In the Wright and Lindesay survey, the proportion of patients found to be suffering from dementia varied from under 20% to nearly 100%, indicating major differences in patient selection and clinic function. Similar surveys are varied in their findings. Luce et al[90] reviewed 100 referrals to a memory assessment service and found that about 57% of attendees had probable or possible dementia; the remainder had other conditions or cognitive deficits that did not meet the criteria for dementia. When Bannerjee et al[91] examined the diagnostic profiles of people referred to a memory assessment service they found that 63% of people referred to the service had some form of dementia, with the remainder having either other conditions or no illness.

In practice, in the UK, many people with dementia never receive a diagnosis. Using prescription rates of cholinesterase inhibitors as a proxy for the diagnosis of Alzheimer's disease, the NAO found that the UK was in the bottom third of EU countries in diagnosing people with dementia. This was before NICE guidance suggested the drugs should be restricted to a smaller group of patients[92]. *Facing Dementia*[93] showed that the reported time taken to diagnose Alzheimer's disease, after the symptoms are first noticed, is 32 months in the UK; longer than France (24 months), Spain (18), Italy (14) and Germany (10).

7.2 Memory Assessment Service in Leicester

The Memory Assessment Service in Leicester is integrated in Outpatient Departments and other clinics in the city. This means that they are not exclusively focused on memory assessment. There are four catchment areas, south west and south east, north west and north east Leicester. The service is linked closely to the

2 Community Mental Health Teams (CMHTs), which provide multi-disciplinary assessment and care for older people, including those with dementia, in the city. The Memory Assessment Service is provided by Leicestershire Partnership Trust (LPT), whilst the CMHTs are provided by both LPT and Leicester City Council (LCC).

The memory assessment component of these outpatient services have developed through custom and practice, in response to a perceived need. This means that the Memory Assessment Service has never been properly commissioned; although there is a process currently underway to commission it as part of the implementation plan for the national dementia strategy.

Recommendation: The Memory Assessment Service should be properly commissioned, incorporating methods of review and challenge to monitor effectiveness.

The Memory Assessment Service in Leicester offers assessment, diagnosis and therapy for people with dementia; it aims to facilitate early identification of the illness, in line with the vision of the NDS. The severity of the deterioration in cognitive function is defined by a global assessment which includes a cognitive function assessed by structured examinations, such as the MMSE score.

Each Memory Assessment Service clinic is held 2 to 3 times per week, with each serving 7 to 8 patients. Referrals to the service are made by primary and secondary care, residential and nursing homes. Whilst the aim of the service is to facilitate early diagnosis, much of the workload also currently comprises the care of those who already have a diagnosis of dementia whose condition has worsened. The need to be seen by clinicians at the Memory Assessment Service has always been greater than the clinical capacity. The average waiting time to be seen is about 6 to 8 weeks, with some people who are waiting much longer before they are able to access an assessment or reassessment.

Every clinic has a ratio of more follow up cases to new ones. One of the main reasons for this is that currently there is no agreed means to discharge on-going patients elsewhere for longer term follow up and monitoring. In addition, the absence of locally agreed shared care arrangements means that the cholinesterase inhibitor medications, which are used to treat Alzheimer’s disease can only be prescribed by experts in the field of old age psychiatry. As it currently stands, if patients are discharged back to primary care they would no longer have access to the medication they require. The need for shared care arrangements is even more important given the impact of the recent review of the NICE technology appraisal guidance 111 in which donepezil, galantamine and rivastigmine are recommended as options for managing mild as well as moderate Alzheimer’s disease.

Given this workload, one way of better utilising the expertise on offer at the Memory Assessment Service, is for service to focus on the cases in which diagnosis is complex; such as distinguishing between normal ageing and dementia.

The latest NICE technical appraisal recommends that memantine be used an option for managing moderate Alzheimer’s disease for people who cannot take AChE inhibitors, and as an option for managing severe Alzheimer’s disease. Prescription of memantine is also recommended as a way of reducing the high levels of anti-psychotic prescribing for the behavioural symptoms of dementia, such as aggression, agitation, shouting and sleep disturbance.

Clinicians estimate that, as a result of the recommendations of the NICE technical appraisal, there is likely to be an increase in the prescribing budget of an estimated £1.2 million for Leicester, Leicestershire and Rutland over the coming year or so. So a review of the local prescribing of anti-psychotic medication is required to ensure that the Memory Assessment Service is aligned to the findings of the report, *The use of anti-psychotic medication for people with dementia*[94] (Bannerjee, 2009) and the guidance in the latest NICE technology appraisal guidance.

Recommendation: The primary care model should review the use of anti-psychotic medication in the context of support systems existing for providing non-drug treatments and a review of the skills available for managing people with dementia in care homes.

7.3 Developing the Memory Assessment Service in Leicester

The local Memory Assessment Service should be commissioned to provide good quality early diagnosis and intervention for patients with mild and moderate dementia, based on criteria laid out in NICE Clinical Guideline 42[95]. The aims of the service, which are outlined by the Department of Health in the Dementia Commissioning Pack could include:

- Effective diagnosis (i.e. high diagnostic accuracy including sub-typing) made early in a timely manner
- Effective communication of the diagnosis to the person with dementia and their family
- Advice on appropriate treatment, information, care and support after diagnosis.

The objectives of the service should be:

- to promote and facilitate early identification and referral and encourage eligible patients to attend assessment
- to provide a high-quality accurate diagnosis of dementia that is communicated in a person-centred way to both the person with dementia and their carers and which meets the individual needs of the person with dementia and their carers
- to provide diagnosis early in the disease
- to ensure that the service is readily accessible and meets the range of needs of the local population, including minority groups
- to ensure that people with dementia and their carers have appropriate information that allows them to manage their care more effectively along the pathway and understand how to access other assistance
- to engage people with dementia and their carers in decisions about the care options available to them, including the development of personal care plans
- to ensure continuity of care across the pathway and integration with other care providers
- to ensure that the service is delivered in a considered, timely and co-ordinated manner

- to provide opportunities for people with dementia to be included in research studies.

Referral to the Memory Assessment Service should be a clinical decision based on the possibility that the individual presenting in primary care has mild to moderate dementia. This will be made by the GP on the basis of presenting symptoms, a review of past history and the exclusion of other acute medical reasons. The GP should produce a brief, objective measure of cognition as part of the referral information arrangements, consistent with NICE Clinical Guideline 42, as outlined in Chapter 6 of this needs assessment. The Memory Assessment Service should be for people with mild to moderate dementia.

Adults should be referred to the memory service if they meet the following criteria:

- The person is presenting with symptoms consistent with suspected dementia rather than a physical or functional mental illness.
- The person does not have an existing clinical diagnosis of dementia.

There is also evidence that a service of this nature can release funds back into health and social care systems[96]. Diagnosis of people with severe dementia could take place in primary care, with or without the support of specialist dementia services.

Where the diagnosis is one of no illness, the patient should be notified of the outcome and the information shared with the patient’s GP. Where there is a diagnosis of another illness it would be expected that the Memory Assessment Service should share the diagnosis with the patient and, if it is appropriate, initiate urgent treatment or referral for physical or mental disorder if required and then discharge to GP. The Memory Assessment Service provider should give advice on further treatment needed and shall share this information with the patient’s GP.

Where there is a diagnosis of dementia commissioners would expect that the memory service provider should give a clear and full explanation of the diagnosis, prognosis and the treatment plan. The service provider should address any initial concerns or requests for information from patients and their carers and families. In cases of dementia where medication is available, the service provider should discuss the diagnosis, prognosis and further care, including medication as part of the treatment plan. Where the diagnosis is one of mild cognitive impairment (MCI) the memory assessment provider shall share the diagnosis with the patient and the patient’s GP. In such cases the patient should be discharged to their GP, who should be encouraged to re-refer the patient if the clinical picture changes.

With regard to the overall outcomes from the Memory Assessment Service, there are potential links to the NICE quality standards and NHS outcomes framework, giving 3 potential headline outcomes focusing on an increase in the proportion of people with dementia having a formal diagnosis and the quality of care received. The potential outcomes for the commissioned memory assessment service could be:

- Increase in the proportion of people with dementia having a formal diagnosis compared with the local estimated prevalence (target 80%; 2256 people in Leicester)
- Increase in the proportion of people with dementia receiving a diagnosis while they are in the mild stages of the illness
- Increase in the number of patients and carers who have a positive service experience

Recommendation: As a specialist service the Memory Assessment Service should be commissioned to focus on individuals presenting in primary care with symptoms of mild to moderate dementia (Cluster 18) and the treatment of those people in whom the disease has significantly altered (Clusters 19 and 20).

Recommendation: The Memory Assessment Service provider should engage with commissioners and primary care to develop shared care agreements so that people with dementia will have access to the treatment and care they require.

8. Meeting carers' needs

8.1 Evidence of carers' views

National policy initiatives, such as *The Carers' Strategy*, *Putting People First* and *Think Local, Act Personal*, focus on the experience of people in receipt of care and the needs and views of their carers. Evidence from national and local consultations, individual interviews and focus groups offer experiences of carers, and compelling testimony to the difficulty of living well with dementia.

The husband of a woman with dementia in a residential home said:

"I would go home and cry. She (my wife) hardly knew me and I don't think that she knew where she was – but she used to beg me to take her with me. The care staff had to try to distract her to stop her clinging to me." [97]

From the same leaflet a daughter of a man with dementia said:

"My dad deteriorated before my eyes. He seemed to disappear – and I thought – no one knows who he really is. No one knows that he was once someone really special with enormous talent." [98]

Dementia usually progresses from mild disturbances of recent memory and abstract thinking through to a late stage, which can be characterised by loss of identity, unintelligible speech, incontinence and impairment of mobility[99]. The person with dementia therefore becomes increasingly dependent on daily care and supervision. Care needs include support with activities of daily living, such as washing, dressing, eating and toileting.

Much of the burden of care falls to informal carers; these are most likely to be spouses or children[100]. Carers often experience social isolation, stress and high rates of depression[101] [102], yet their own needs often go unmet[103]. A carer's health and well being is often the cause of a person's admission to nursing or residential care. Carer's health may also be related to the issue of elder abuse by relatives and other informal carers.

8.2 Role and effectiveness of respite care

For carers of people with dementia, respite care seen is a potentially important way of maintaining the quality of life for themselves and the people for whom they are caring. A systematic review of 10 randomized controlled trials, 7 quasi-experimental studies and 5 uncontrolled studies[104] showed that for all types of respite, the effects upon caregivers were generally small. However, although many studies reported high levels of caregiver satisfaction, there was no reliable evidence to suggest that respite care delays either entry to residential care or adversely affects frail older people.

A review of respite services and short-term breaks for carers for people with dementia had mixed findings with some policy implications[105]. The benefit of respite to some extent depended on whether the break was aimed at preventing future service use (for instance residential care) or for the immediate relief of the carer[106].

The review looked at a number of models of respite care and feedback from consultations with carers. It found that day care services, those which are provided outside of the home but not involving overnight stay, were of benefit to carers and the person with dementia. Whilst there was some evidence to suggest that day care may prevent entry to long term care, the evidence as to whether day care is cost effective was equivocal; 2 economic evaluations suggested that day care might be cost effective whereas 2 suggested that day care could provide higher benefits only at a higher cost.

There were also mixed findings with regard to the impact on the carer and the person with dementia. Some studies showed improvement or stabilisation for the person with dementia, whilst some showed no positive effects. Similarly for carers some studies showed improvements in physical and mental health and wellbeing, whilst others showed no positive effects. With regard to accessing day care services, problems related to regular attendance at day care acted as an obstacle to using such services.

Evidence for the effectiveness of respite breaks away from home for one night or more was also equivocal. Organising such breaks was perceived to be difficult. There were some physical and emotional benefits for the carer, with increased sleep for example, but also guilt in using respite services. Some people believed that it helped them to continue in the caring role. For the person with dementia, however, there was mixed evidence as to the benefit on their activities of living there was little evidence that overnight respite delayed admission to long term care.

Other models which were considered included in-home and host family respite. In-home care involves a care worker sitting with the person with dementia. Host family respite sees the person with dementia and the carer take breaks together by staying with another family.

Evidence suggests that carers have high levels of satisfaction with in-home respite care and that there was some advantage in maintaining family routines. It was difficult to separate the impact of in-home respite from the demand for other types of respite care or the reduction of the demand for long-term residential care. Carers reported positive outcomes from host-family respite, especially when they wanted to spend time together with the care recipients. It was generally preferred to the alternative of the person receiving care staying in a residential home.

There was some evidence to suggest that support packages which comprise different services may delay permanent admission to long term residential care. However, a minority of studies show that residential respite can worsen service user health. The Social Policy Research Unit (SPRU) found that sometimes there was a contradiction between the value that carers put on respite care and their actual experience of respite; this was also a finding in the Social Services Inspectorate report *Getting the Right Break*[107] . In *A real Break*[108] there is stress laid upon defining breaks, making it clear who they are for, preparing for the break as well as the quality of the service. The SPRU team produced a respite pyramid to consider in planning respite services (see Appendix 8). This emphasises the need for respite care to be based on individual assessment, on going evaluation and that respite should be appropriate to the needs and circumstances of the carer and the care recipient. This model also suggests that respite services are most effective when they are underpinned by knowledgeable and supportive doctors, responsive social services, accessible information and supportive care networks.

8.3 Evidence from Department of Health demonstrator sites

The University of Leeds produced an evaluation of the Department of Health Demonstrator Sites aimed at improving the health and wellbeing of carers as part of the National Carers' Strategy. These sites looked at the quality and effectiveness of a range of approaches towards breaks for carers, the delivery of annual health checks and ways of supporting carers in NHS settings[109].

The sites showed that strong multi-agency partnerships, inclusive of voluntary organisations, are required to identify and engage carers. Such links can be developed without an unduly disrupting health and social care workloads. However, it was found that to encourage GPs to engage with carer support, some sites needed to adopt special approaches and invest considerable effort.

Most carers felt they benefitted from the services offered. Flexible and personalised breaks were shown to be of positive benefit for many carers. There was evidence that this had the potential to prevent the deterioration of carers' health and to sustain carers in their caring role. Health checks led to sustained self-care and healthier behaviour for some carers.

The evaluation report also found that carer support can save costs to the providing organisation and to the health and social care sector generally. These cost savings included the prevention of hospital or residential care admission, supporting carers to sustain their caring role, earlier identification of physical and mental health problems in carers, efficiency savings in GP practices and assisting carers to undertake paid work.

With regard to policy recommendations, the evaluation and the government consultation on the *Future of Care and Support* were considered by the authors as an opportunity to put some of the findings into practice. These included:

- Involving a diverse range of carers in service development. These carers would be suitably trained and arrangements for their engagement based on flexible local partnerships, involving agencies which are trusted by carers which may be outside the health and social care system.
- A recognition that effective carer support at the local level should always include varied carer support services, which can be adapted to meet individual needs.
- Better support for carers with: health problems and stress; information on how to access suitable support, services, equipment and home adaptations for those they care for; income maintenance and pensions protection during and

after caring; self-care, healthy lifestyles and maintaining a life outside of caring; access to education, training, work and leisure; emergency planning; and how to access occasional or regular breaks from their caring role.

- Hospitals should routinely identify and support new carers, centring their efforts on wards where patients have received a new diagnosis or are due to be discharged and on out-patient clinics. Support should be timely and co-ordinated.
- Every GP practice should be encouraged to identify a lead worker for carer support, who can assist in carer identification, help in referring carers to suitable local services, and ensure carers' access to health appointments and treatments is not impeded by their caring circumstances. These workers may require carer awareness and carer support training. The action guide 'Supporting Carers', for GPs and their teams, published by the PRTC and the RCGP in October 2011 provides detailed suggestions for practical ways of taking this forward (PRTC and RCGP, 2011).
- All staff who interact with carers, in hospitals, GP practices, local authorities and in the voluntary sector should be trained to consider how caring responsibilities can impact on a carer's health and well-being and be equipped to advise on how a carer can access a health and / or well-being check.
- All relevant organisations should regularly offer carer awareness training to their staff.

8.4 Supporting carers in Leicester

This needs assessment has shown that the contribution of carers in supporting vulnerable people has been acknowledged in National Carers Strategy. If families and carers did not care for their loved ones, it would cost the government £104 million a year. LLR local authorities currently offer a number of services to support people caring for someone with dementia including, advice, information, advocacy services and Carers' Support Grants. These can be paid as a personal budget to enable a carer to buy support services to assist with their caring role, such as respite care; including short stays in residential accommodation, 'respite at-home', short-stay sitting services, day care services, befriending services and dementia cafes.

All carers of a social care client can be offered a carer's assessment. In 2011/12 1,233 carers received an assessment. As a result of receiving a carers' assessment or review, carers over the age of 18 receive support in the form of respite or a carer specific service or they receive information and advice. According to carers' assessment data, in the period 2011/12 there were 705 (57%) carer's services supplied and 528 (43%) cases where information and advice was given. For adults aged >65 advice and information is more likely to be given. The services provided include:

- Domestic Tasks - examples include shopping, cleaning and laundry.
- Meal preparation - meal preparation is for the person being cared for to give the carer a break from cooking.
- Day Care - If the carer needs a bit of a break from caring from someone, we could provide one day a week day care. However, the person being cared for must be in agreement and would need to benefit from this service.

- Respite Care - You may need a longer break from caring for a holiday, for example.
- Professional support - this could be advice and/or emotional support.
- Equipment - there may be equipment that could benefit a carer.

Carer assessment and support is usually initiated once a person living with dementia comes into contact with services. This emphasises the importance of early diagnosis; as people caring for someone with dementia who have not accessed services are often missed. So some carers are not aware of how to access early stage advice and information about support, and that an individual presents to services at a time of crisis when a carer cannot cope[110].

Feedback from local stakeholders, including users and carers, has been consistent with the national findings. This feedback includes a series of engagement events with stakeholders, some of which were externally facilitated and local surveys. One local survey suggested that carers generally used shorter breaks (<24 hours), rather than longer ones. 34% of carers had used services providing a break from caring of 24 hours or less compared with 26% who had used breaks services lasting more than 24 hours. Reasons for not accessing services include concerns that the person they were caring for would refuse the service, the cost of services, information about services and the opportunity to choose a holiday rather than a conventional service. The quality of current services did not appear to be an issue. About half of the respondents indicated a willingness to use Direct Payments.

Survey respondents were asked first which services they had heard about. The ‘most known’ services were breaks purchased via the Carers’ Personal Budgets scheme (48%) and residential respite organised by the council (46%). Respite at home services had a lower recognition rate (38%). The service with the lowest recognition was Adult Placement/Shared Care (5%).

Other questions asked about services actually used. 52% of respondents had used at least one of the breaks services. The most commonly-used services were breaks purchased via a Carers’ Personal Budget (28%) followed by residential respite organised by the council, although at half of the level, 14%.

The group that had used breaks services had high satisfaction rates: 40% very satisfied and 46% quite satisfied, with most of the remainder opting for the middle rating of ‘neither satisfied nor dissatisfied’. 40% of the service-using group said that they may have used other services if they had known about them.

The group of questions for carers who had not used services firstly asked respondents to identify which barriers to accessing services were significant to them: 22% said that not knowing about the services was an issue, but there were higher scores for concerns about cost (24%) and for the care recipient refusing respite (23%).

All respondents were asked whether they would be interested in using a Direct Payment to organise and purchase respite or other breaks: 49% said they would be, although more than a third of these carers said they would require help to use the

Direct Payment. The remaining half of respondents split almost equally between “I would not be interested” (24%) and “don’t know” (27%).

There are many barriers to accessing breaks, such as information and acceptability and cost. For Mansfield[111] the future focus of work to improve carer experience includes ensuring that ‘time off’ is adequately covered at the outset in the assessment of carers’ needs. It should also include the provision of information about breaks options, direct payments (and the support available to assist with using them) and charging. In addition, there needs to be increased collaboration with service users and carers to increase the acceptability of options to people with care needs.

These ideas are reinforced by the carers’ strategy for LLR, currently being updated. This states a vision for carers in Leicester, Leicestershire and Rutland in which:

- Carers are identified early on in their caring role
- Carers’ needs are identified early on and that early action is taken to support them in their role helping them to retain their independence
- Carers feel their contribution is recognised, that they are listened to and that their opinion is respected
- Carers have a meaningful contribution to the process of planning support and services
- Carers are supported to fulfil their educational and employment potential
- Carers can access personalised support to enable them to have a full life, both in their families and outside
- Carers are supported to remain mentally, emotionally and physically well
- Carers are supported to be independent and remain independent

In order to fulfil this with regard to carers of people with dementia, there needs to be flexible approach to respite care, in particular greater provision of respite in the home and access to personalised budgets. Carers will also benefit from the improvement of services along the dementia care pathway, in particular with the impetus towards memory assessment and early diagnosis, better communication with dementia care co-ordinators, better communication with primary and secondary care providers and a highly trained workforce providing health and social care in the community or in care homes.

Recommendation: All carers should have a carer’s assessment

Recommendation: Carers’ assessments should include information about breaks options.

Recommendation: There should be a wide variety of models of respite care tailored to individual needs and available to carers using personalised budgets.

9. Social Care

9.1 Role of social and community support in dementia care

Social and community support services are of great importance in the care of people with dementia. The services commissioned by the local authority may range from the provision of information to practical help such as domiciliary and respite care. This care is based upon an assessment of need. Since the 1990s there has been a concern that the resources which are available to local authorities are not sufficient to meet the needs of the population[112], and that this has contributed to the perception that there has been a decline in the quality of provision.

Liaison between NHS and local authority departments for the care of people with dementia has not always been effective. An underlying cause of this is the division between NHS care, free at the point of access, and social care provision. As social care is provided outside the NHS, often by local authorities and third sector organisations, charges often apply which are usually means tested. The variation of costs and service provision has also led to arguments about a 'post-code' lottery.

In the past this problem was sometimes resolved by long-stay hospital beds. In the mid-1980s old-age psychiatry services had on average 3.4 long-stay beds per 1000 population aged over 65[113]. However, changes in national policy have resulted in a shift and a decline in bed numbers, with beds now mainly available in nursing and residential homes.

Only 8% of nursing homes cater explicitly for older people with mental ill health. However, the prevalence of dementia in both residential and nursing homes is high, and hidden by poor rates of diagnosis. Darton[114] reported that 67% of admissions to nursing and residential homes have significant cognitive impairment, although only 39% had been diagnosed as having dementia; 34% of all admissions displayed behaviour problems. Given such a high rate of undiagnosed dementia, there are likely to be many more cases in nursing and residential homes. In this context, and given the complexity of looking after a person with dementia, it is not surprising that surveys of homes in the UK suggest a wide variation in the quality of care[115].

General criticism of those nursing and residential homes which are less satisfactory often centres on untrained staff, the inappropriate use of sedative medication, lack of properly structured activity programmes for residents, inadequate documentation and isolation from local communities. Care homes are regulated by the Care Quality Commission[116] and advice in choosing a care home is offered on the NHS Choices website[117]. Sheltered housing may be available in some areas, but may not be suitable for people with nursing care needs.

The NICE-SCIE guideline suggests best-practice advice on the care of people with dementia and on support for their carers. It focuses upon the principles of person-centred care and asserts

- The human value of people with dementia, regardless of age or cognitive impairment, and those who care for them

- The individuality of people with dementia, with their unique personality and life experiences among the influences on their response to the dementia
- The importance of the perspective of the person with dementia
- The importance of relationships and interactions with others to the person with dementia, and their potential for promoting well-being.

The principles emphasise the imperative in dementia care to consider the needs of carers, whether they are family and friends or paid care-workers, and to consider ways of supporting and enhancing their input to the person with dementia. This is described as ‘relationship-centred care’ and is the focus of much of the developments in national policy guidance.

Overall, as with primary care, the challenge to provide better social care is to address the substantial gap between met need and expected need. Ideas as to how to meet this gap, which have emerged through analysis and consultation include:

- An integrated approach to meet the needs of older people with mental ill health
- A service specifically targeted at younger people with early onset dementia
- Better training for staff providing care to older people with dementia.
- Better service provision specifically designed to meet the needs of people with dementia (e.g. respite care or intermediate care).
- Better local authority residential and respite provision.
- Expansion of the range and capacity of services to support carers.
- Expansion of the service provision for BME older people with mental health needs
- Targeted provision to maintain engagement of people with dementia and their carers in the community
- Addressing the disproportionate investment in specialist resources compared to investment in lower level voluntary and community sector services to specifically support people with dementia and their carers.
- Addressing the limited capacity in the provision of specialist community mental health teams to undertake their educative and liaison roles.

9.2 Social and community support services in Leicester

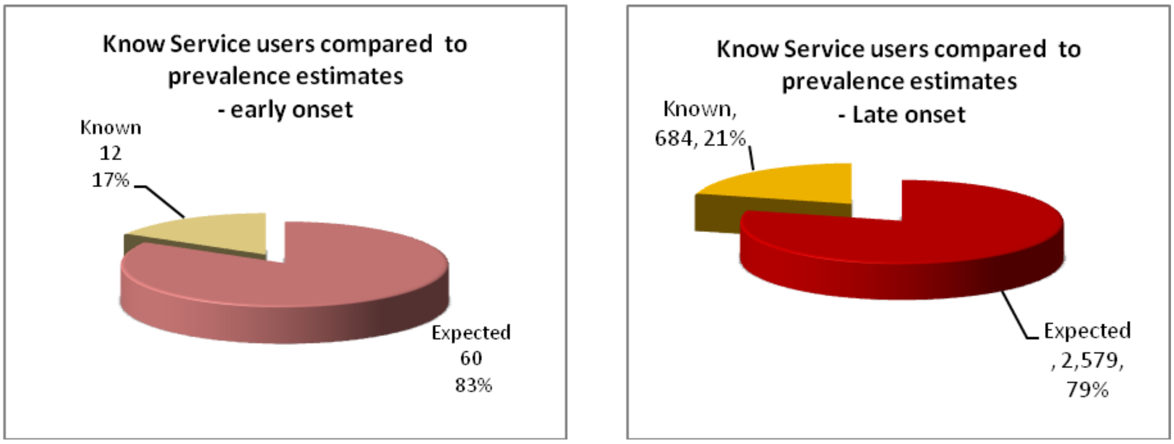
Available evidence suggests that support services exist and are being accessed by people with dementia both at home and in residential accommodation. However, the numbers in receipt of care are below the expected prevalence of dementia.

In Leicester nearly 1,600 people aged over 65 were receiving social care for Mental Health problems in 2010-11. 288 people over 65 years had completed social care assessments for mental health problems in that period. Of these, 97 (33%) were recorded as dementia[118]; this is less than 4% of the expected number of people estimated to have dementia in Leicester.

The Referrals, Assessments and Packages of Care statutory returns to central government show there were 255 living in Leicester with dementia receiving support from Adult Social Care in the year 2007/08, (240 People aged 18-64 and 11 people aged 65 and over). The majority were receiving support to live at home. Again, this is far fewer than the expected number.

Carefirst records show that about 680 people with dementia received support in 2007/08. The majority of these were women and the largest proportion of social care support is for residential and home care. Those people in receipt of this are more likely to be from White/White British or Asian/Asian British ethnic backgrounds.

Figure 14: Dementia service users known to social care compared to expected prevalence



Given that only about 680 people with dementia are known to be in recipt of social care services, compared with approximately 2,700 people with dementia living in Leicester, there is a substantial gap. Whilst those who are not receiving care may be accessing support from the voluntary sector or paying for themselves, the fact remains that there is a large proportion of unmet need. This gap is likely to increase with the ageing population.

Table 9.1, below, shows that the demand for services differs by ethnicity and, in consequence, the demand for services could change as the proportion of older people from BME backgound in the local population increases.

Table 9.1: Current provision of service to users with Dementia by ethnicity

Ethnic group	Services	Clients	% of demand	% of ethnic demand
Any Other Ethnic Group	Resid. Care - Lt	2	0.29%	0.29%
Asian/Asian British Ethnic Backgrounds	Day Services / C.S.S	8	1.17%	16.33%
	Direct Payments	1	0.15%	2.04%
	Family Carer Respite	1	0.15%	2.04%
	Home Care	28	4.09%	57.14%
	Mobile Meals	1	0.15%	2.04%
	Nursing Care - Lt	5	0.73%	10.20%
	Resid. Care - Lt	5	0.73%	10.20%
Black/Black British Ethnic Backgrounds	Day Services / C.S.S	5	0.73%	31.25%
	Home Care	5	0.73%	31.25%
	Mobile Meals	2	0.29%	12.50%
	Nursing Care - Lt	2	0.29%	12.50%
	Resid. Care - Lt	2	0.29%	12.50%
White/White British Ethnic Backgrounds	Day Services / C.S.S	43	6.29%	6.97%
	Direct Payments	3	0.44%	0.49%
	Extra Care	5	0.73%	0.81%
	Family Carer Respite	19	2.78%	3.08%
	Home Care	205	29.97%	33.23%
	Interim Res Care	2	0.29%	0.32%
	Mobile Meals	27	3.95%	4.38%
	Nursing Care - Lt	66	9.65%	10.70%
	Professional Support	1	0.15%	0.16%
	Resid. Care - Lt	239	34.94%	38.74%
	Resid. Care - St	7	1.02%	1.13%

9.3 Personalisation

In those cases where people require ongoing support there are a number of services available, depending on the level of the individual assessed need. Services are aimed at supporting an individual to live as independently as possible, for as long as possible. There are some care options available to support people with dementia and their carers, of which perhaps the most important is personalisation.

This needs assessment has shown that Personal Budgets were introduced as part of the National Personalisation Agenda in adult social care. These budgets aim to give people much greater choice and control in the services arranged to meet their needs for care and support. The aim is to ensure that individuals eligible for social care services are allocated an amount of money to help arrange their support, based on their assessed need and to deliver agreed outcomes. The budget may be taken as a direct cash payment or managed services. It means there has been a significant change to the way adult social care services are provided.

There are four areas on which councils and their partners have focussed to help make sure services become more personalised and to get the right results for people.

- **Universal services** – providing general support and services available to everyone locally including things like transport, leisure, education, health, housing, community safety and access to information and advice.
- **Early Intervention and Prevention** - support available to assist people who need a little more help, at an early stage to stay independent for as long as possible e.g. assistive technology, reablement etc.
- **Choice and Control -** is about giving people the freedom to choose the services that suit them best, and to control how and when they receive those services.
- **Social Capital -** is about how society works to make sure everyone has the opportunity to be part of a community and experience the friendships and care that can come from families, friends and neighbours.

Recent changes to direct payment rules have enabled more people living with dementia and a nominated suitable person to access direct payments, where issues of mental capacity may have prevented them from participating in the scheme in the past.

There is a national drive that by 2013 all individuals accessing support from social services should be offered direct payments to meet their identified needs. This underpins the transformation and future direction of travel for adult social care, allowing more individualised support and enabling people to live quality lives independently for as long as possible.

Leicester City Council has implemented Self Directed Support, with all new service users accessing personal budgets and existing users transferring following a review. It also has an established reablement service with health and social care input. The service provides intensive free care and support for 4 to 6 weeks; aimed at enabling a person to regain and maintain their independence. The objective is to reduce the need for long-term social care and support packages. Leicester City Council is in the process of re-designing its reablement service to create a fully integrated health and adult social care pathway, including a crisis response team to prevent people going into hospital, and enabling those being discharged from hospital care support for approximately 4 weeks. This also includes specific services for people with dementia. The service will also support those living in the community that need a short period of reablement. The service re-design will be under pinned by joint commissioning arrangements, joint working arrangements and a joint investment plan.

Recommendation: To ensure that people diagnosed with dementia are given a personal budget, if eligible for support and those who are not, are given appropriate advice and information.

9.4 Other services in the community

One of the benefits of early diagnosis is that there in place there is that those people who have been newly diagnosed with dementia, and their carers, will receive written and verbal information about their condition, treatment and support options. This will also give people with dementia the opportunity to discuss and make decisions, together with their carers, about the use of advance statements, decisions about treatment, priorities of care and power of attorney[119]. To facilitate this a number of different initiatives, provided under the umbrella of social care, should be better incorporated into the patient pathway.

In Leicester the Dementia Care Co-ordinators have a role in providing advice and support to people with dementia and their carers. There are currently 8 dementia care co-ordinators, following the successful one year pilot in which one co-ordinator looked after the needs of 179 people. Of the 8 co-ordinators currently in post, 6 are based in localities, with the other co-ordinators focusing on re-ablement and the single point of access to the service. The co-ordinator role is to improve the quality of life for people with dementia and their carers by providing links to information and support, resources and partnership working with available services. The co-ordinators provide advice on assistive technology and social support throughout the disease process.

In the pilot year they were particularly successful in liaising with the current memory assessment service, although links with primary care were disappointing. Yet, in a service in which early diagnosis is the key, there is a clear role for communication about advice and support. The dementia care co-ordinators are essential to the delivery of practical information to help and advise people with dementia and their carers.

Recommendation: The dementia care co-ordinators should be commissioned solely to work with people with dementia and their carers. Their role should be to provide advice and support across the patient pathway. Access to the service should be from a number of points, including self-referral, voluntary sector, primary, secondary and social care. To engage better with primary care, there should be closer links between dementia care co-ordinators and GPs in their different localities.

In Leicester the memory cafe offers the opportunity for people to discuss issues around dementia as well as getting peer support and professional advice. It is planned that the cafes will feature discussions or speakers on topics such as benefits and assessments, keeping safe in the home and dealing with the emotional impact of dementia. They are free to attend and carers are welcome to come along either on their own or with care recipient.

Currently there is one café, based at Eyres Monsell Community Centre, though future venues are planned at African Caribbean Centre in Highfields, Belgrave Neighbourhood Centre and New Parks Community Centre.

Assistive Technology is provided by Leicester City Council following an eligibility assessment by Adult Social Care. The technology can be a piece of equipment or a service that can enable a range of people to remain independent and safe in their own homes, by helping them to manage risks or making it easier to fulfil activities of daily living. It can help people to remain independent by reminding them to take medication, allowing safer cooking, helping people to keep in touch and alerting emergency services more quickly. The full list of solutions includes a picture phone, voice alarm reminders, a falls detector gas and smoke sensors[120].

9.5 Care delivered in residential and nursing care homes

There are 108 care homes in Leicester; most appear to have some residents with dementia, although 58 are listed as doing so according to www.carehome.co.uk. Some of the residents will never have been diagnosed with dementia. Improved care in nursing and residential homes is crucial to the development of an improved dementia care pathway.

Past evidence suggests that despite dementia care being a core function of the health and social care workforce, formal care services are struggling to deliver good quality dementia care; identifying the lack of an informed and effective workforce. *Home from home*[121] found that staff members in many care homes do not have the skills required to provide good quality dementia care. It is vital therefore for the commissioned services to include a range of quality standards, such as those presented by the Care Quality Commission and NICE and the local LLR wide Dignity in Care Programme.

The standards which need to be met are at least that people with dementia should have an assessment and ongoing personalised care plan, that they receive care appropriate to their needs, including palliative care and care for anxiety which may be caused by non-cognitive symptoms. There are different mechanisms which may be used to try to meet these standards.

The Quality Assessment Framework (QAF) is a commissioning tool which aims to improve quality care. It may be used to ensure that care recipients have an assessment of their support needs and any associated risks, that they have an up-to-date support and risk management plan and that their care managed by skilled staff and involve other professional carers as appropriate.

Another lever for improving the care delivered in care homes, adopted by the local strategic work streams, is to focus on the development of the local workforce to meet the training and skills of the local service providers, as laid out in the objectives of work stream 5 of the LLR Joint Commissioning Group. This is important because national focus group evidence shows how people with dementia and carers viewed the care which they received from nurses. Some evidence is highly critical:

“They stand at the bottom all laughing at you….And I didn’t take that….People laugh at people with Alzheimer’s but you don’t expect nursing staff to.” [122]

The themes in this particular focus group evidence also included the need for dignity and respect, person-centred care and communication. Again the feedback is testimony of the difficulty in caring for someone with dementia. For instance, carers speaking about the toileting needs of someone with dementia:

"In this particular home they change their pads at certain times of day, i.e. morning, lunchtime, afternoon 4pm and eve. But not everyone needs to be changed at the same time. I got shouted at by one of the carers; 'she was changed at lunchtime'. May well have been, but she's dirty now. These people are not in care homes for a week, but have often been in there 12 or 15 years. So surely she can be changed not by the clock but by need. But you can't keep going to the nurses as they don't listen." [123]

Recommendation: All nursing and residential home staff should have training about the needs of people with dementia and their carers appropriate to their role in the Dementia Care Pathway.

Another important approach, and one which is part of the *National Dementia Strategy* implementation programme, is to develop a service to support care homes to provide better care. The aim of this would be to provide specialist dementia expertise to give advice and support in primary care for better assessment and management of people with problematic symptoms of dementia and other complex presentations. More timely appropriate interventions should enable people to remain at home for as long as this is their preferred place of care and could reduce the number of unplanned admissions and readmissions to hospital. The potential outcomes for improved community based services could be:

- Reduction in the use of antipsychotic medication for people with dementia in care homes, at home and other residential settings
- Contribute to a reduction in unplanned admissions and readmissions of people with dementia to general and community hospitals from care homes, home and from other residential settings
- Increased patient and carer satisfaction

This specialist dementia service would be designed to provide sufficient capacity and skilled resources to advise and support primary care practitioners in the treatment, care and management of people with problematic symptoms of dementia or other complex presentations, whether they are living at home, in care homes or other residential settings. It could work with relevant health and social care organisations to ensure that service protocols are in place to raise awareness of the service and to deliver a seamless service for patients. Relevant services would include GPs and primary health care teams, other community health services, acute care, including hospital discharge planning services, memory assessment services and voluntary organisations. During care home visits, it would be expected that the service provider will take all opportunities to model good standards of care and ensure knowledge transfer of good practice with care home staff.

Recommendation: There should be a specialist community care team to assess the needs of people with dementia living at home or in care homes. This team will advise carers and other local health and social care providers about the assessment and management interventions for patients with problematic symptoms of dementia.

10. Secondary Care

People with dementia who are physically ill may require acute in-patient care in a general hospital. The care for those people, who have dementia and a physical health problem, often by necessity, occurs on wards where there are patients who do not have dementia. In some areas there has been a focus on augmenting the geriatric medical team with clinicians who have mental health experience.

It is interesting to note that, compared with older people in general the rate of cognitive impairment is raised among elderly patients admitted to acute hospital[124]. Cognitive impaired patients are often admitted with delirium, or become delirious while in hospital. They have, on average, a significantly longer hospital stay than other patients of the same age[125], and they have a less favourable prognosis[126]. Despite the high prevalence of cognitive disorders in the elderly, past evidence suggests that clinicians are often unaware that a problem exists unless the patient's behaviour is disturbed[127].

This is a common problem nationally; for the mental health needs of older people often remain undetected, with the result, in some cases, that appropriate treatment is not initiated[128]. The NAO found that some general hospital services even worked hard not to make a diagnosis of dementia for fear it would delay discharge.[129] Failure to diagnose dementia is an independent predictor of a poor outcome for the patient and for the service.

People with dementia often have complex problems and may stay in hospital for longer than other people who go in for the same condition. There is often a lack of co-ordination between the hospital and care providers at the point of discharge. The longer length of stay may worsen symptoms of dementia and be detrimental to the individual's well-being. Discharge to a long-term residential care home becomes more likely and antipsychotic drugs are more likely to be prescribed[130]. The dementia commissioning pack suggests that although there are examples of good quality general hospital care, where the challenges of dementia are recognised and addressed, there are also widely reported cases of substandard or neglectful care[131].

10.1 Emergency inpatient admissions for dementia at UHL

There are relatively few hospital admissions with a main diagnosis of dementia; in 2010-11 there were 143 admissions, equivalent to around 40 per 10,000 over 65s, which is an increase on the previous 2 years.

These admissions had an average length of stay of over 40 days with approximately 25% discharged within a week (13% within 1 day, and 12% within 2-6 days), 25% discharged between 1 week and 28 days, and 50% staying in hospital for over 28 days.

Table 10.1: Emergency hospital admissions with a main diagnosis of dementia for Leicester residents

Year	2008-09	2009-10	2010-11
Bed days	4488	3795	5761
Average Length of stay	45.4	42.0	41.8
Emer adms for dementia	109	102	143
Population 65+	35665	35676	35639
Crude rate per 10,000 65 year olds	**30.6**	**28.6**	**40.1**

Data: Hospital inpatient dataset, Secondary uses Service

There were around nine times more hospital admissions with any diagnosis of dementia (main or secondary diagnosis) than for dementia as the primary cause. Where dementia was a secondary diagnosis, around a quarter of the admissions were due to ‘Symptoms and signs’, 18% due to injury and poisoning, 14% due to respiratory conditions and 8% cardiovascular conditions.

Table 6.2: Emergency hospital admissions with any diagnosis of dementia for Leicester residents

Year	2008-09	2009-10	2010-11
Bed days	16087	16813	21289
Average Length of stay	16.6	14.9	15.6
Emer adms for dementia	907	1055	1246
Population 65+	35665	35676	35639
Crude rate per 1,000 65 year olds	**254.3**	**295.7**	**349.6**

Data: Hospital inpatient dataset, Secondary uses Service

Figure 16: Primary diagnosis of admissions with any diagnosis of dementia for Leicester residents

Primary diagnosis code	Primary diagnosis description	Adms 2010-11
S72	Injuries to hip, thigh	1008
N39	Other disorders of urinary system	680
J18	Influenza and pneumonia	468
S01	Injuries to head	330
S00	Injuries to head	260
G40	Epilepsy	231
F00	Dementia in Alzheimer's disease	225
S52	Injuries to elbow, forearm	200
R07	Pain in throat and chest	162
R54	Senility	152
		3716

Data: Hospital inpatient dataset, Secondary uses Service

10.2 Emergency Department attendances for dementia

Emergency department (ED) data does not have completed coding for diagnosis, so it is difficult to estimate the number of people attending ED through dementia-related causes. However, it is possible to determine inpatients admitted through ED.

Recommendation: Commissioners should find ways of obtaining more effective coding of the attendance of patients with dementia at the emergency department.

10.3 Secondary care and the dementia care pathway

The importance of general hospital care to the dementia patient pathway has been further emphasised by work undertaken in a recent survey of patients at UHL. As part of this survey[132], for a 10 week period between February and April 2011, all patients attending the Acute Medical Unit (AMU) at the Leicester Royal Infirmary, aged 70 or over, were assessed for frailty using the local operational definition of frailty and the Rockwood Frailty Score, enabling assessment from the very fit through to those who are severely frail.

Overall, 2,425 people were admitted to the AMU during the 10 week study period, of whom 1,165 (48%) were 70 years or older. It was found that frail people[133] comprise approximately 3% of all Emergency Department attendees at any one time, 10% of all patients on the AMU, and approximately 50% of patients on base wards within UHL[134] [135].

Of those aged >70, 843 individuals were assessed representing 898 separate admissions, some patients having attended on more than one occasion. The mean age was 83.0 years (95% CI 82.5-83.4) and 378 (42.9%) were male. As the survey sought to estimate the prevalence of frailty, individual episodes rather than individual patients were assessed. The UHL frailty criteria characterised 61% of patients as frail and 58% of people had delirium or dementia.

Such a high prevalence of frailty, delirium and dementia in a general hospital setting suggests that there is a case for the development of a multidisciplinary liaison service offering both mental and physical health expertise. The development of a liaison service could provide a standard approach to the assessment and recording of cases. It will also pick up on expertise at UHL for the assessment of a delirium risk assessment tool, which has been developed in partnership with the East Midlands HIEC and De Montfort University.

Such specialist liaison services are advocated both in the national dementia strategy and in NICE/SCIE guideline on dementia[136] as ways of

- Providing support and advice on making the diagnosis of dementia and other mental health conditions

- Providing support and advice on management and care planning, including discharge planning for people with confirmed or suspected mental health problems and behavioural management problems
- Contributing to education and training for hospital staff
- Contribute to the governance, audit and development of policies and procedures for good quality health care.

Recommendation: To develop an integrated service comprising mental and physical health care expertise to provide a standard approach to the assessment and recording of an older person's mental health status upon admission to secondary care.

This integrated service is already being developed, for as part of the 2011/12 Transformation Fund Project, called Frail Older People's Initiatives (Interface Geriatrics), the Frail Older People's Advice and Liaison Service (FOPAL) merged with mental health services for older people with the intention of forming a comprehensive liaison service.

Since the transformation funded FOPAL development, the dementia case finding CQUIN, highlighted in the Prime Ministers Challenge on dementia, has been introduced. FOPAL appears to be ideally placed to contribute to awareness about, and diagnosis of, dementia in the many people who attend secondary care with dementia without a confirmed diagnosis.

The service could provide the necessary expertise to implement a systematic approach to assessment and recording of dementia cases, without which there will continue to be under reporting of the numbers of people living with dementia accessing general hospital care. Between November 2011 and April 2012 907 FOPAL had 907 patient episodes; 401 patients had dementia, of whom 255 required a new diagnosis. Of the 401 patients seen 133 (33%) were referred to the older persons community mental health team, 30 (7%) were transferred to LPT in-patients and 238 (59%) required no further input.

It is important therefore to commission a liaison service combining credible physical and mental health clinical expertise to assess patients with physical health needs and cognitive impairment in both inpatient and outpatient settings. This service should have effective links to memory assessment services, older persons' mental health services and primary care.

The links with primary care are essential, to ensure that any newly diagnosed cases of dementia are added to the register and that the GPs are involved in rationalising prescribed medication and signposting people to support services as soon as possible. Such a multi-disciplinary approach should also improve service user and carer experience of services, ensure that people with dementia are treated appropriately and, with shared care protocols, will also contribute to the diagnosis of people with dementia and ensure that people with dementia have access to appropriate treatment.

There is further evidence to suggest that, if such a service was properly commissioned, there would be an impact on factors such as hospital admissions and a patient's length of stay in hospital care. Over the past 3 years, in UHL, the average length of stay for someone with dementia has been measured as 10.98 days. People with dementia have not been routinely called back to review their cognitive status. It is envisaged that if a multidisciplinary team is commissioned, so that it can assess the cognitive status of the frail elderly patient in outpatient settings it will reduce length of stay. Additional benefits should include a reduction in the number of people discharged to care homes as a new place of residence, a reduction in the prescription of anti-psychotic medication and better experience for patients and carers.

Recommendation: The multi-disciplinary hospital liaison service should incorporate credible mental and physical health expertise to assess the needs of frail older people. This team will facilitate detection of dementia in hospitalised group of patients, by reviewing them, prioritising patients' needs and reduce the length of stay of patients with cognitive issues. Patients diagnosed by the team should be added to the dementia register held in primary care

10.4 Older persons' mental health in-patients

In addition to secondary care in general hospitals, the NHS across Leicester, Leicestershire and Rutland currently commissions 80 in-patient assessment and treatment beds from LPT, located at the Evington Centre. This in-patient facility is designed for people aged over 65 years with organic mental health problems, and are predominantly used by people with dementia. In 2009/10 there were 315 admissions to these beds with an average length of stay of 68 days. The primary reason for admissions related to family/carer breakdown, which contributed to 42% of the total number of admissions. Family/carer breakdown often occurs as a result of an exacerbation in the behaviour displayed by the person with dementia. A review of the admissions data for 2009/10 indicated that:

- the average length of stay was approximately 68 days
- 29% of patients stay over 12 weeks
- 48% were discharged to a care home
- 25% were discharge to a general hospital
- 20% were discharged home
- Of those patients that had a length of stay of less than 6 weeks, 49% were discharged to an acute general hospital

There is a need for commissioners to review the high proportion of discharges to care homes, and a need for more information from this particular secondary care service. It is important that further analysis is undertaken to review the outcomes from these episodes of care and to record the care cluster of the person admitted.

Recommendation: That in-patients and discharges at LPT are analysed, under the new payment by results tariff in mental health services, to provide a greater level of understanding as to the appropriateness of discharge to care homes and the alternatives that could be considered/developed in the future spanning both health and social care options.

10.5 Staff training needs

In *Counting the cost*[137] the Alzheimer's Society explored the quality of dementia care provided in general hospitals and surveyed people with dementia, carers and nursing staff. The report found that carers were dissatisfied with the overall quality of dementia care provided, that people with dementia are staying in hospital far longer than other people who go in for similar procedures and that when individuals do leave hospital they have deteriorated in terms of their physical health; they were often malnourished, dehydrated or constipated. It was also found their dementia had progressed whilst they were in hospital, in that they were more confused and distressed and more dependent.

As with other areas, therefore, there is a need to raise awareness about dementia in secondary care and the training needs of all people involved in secondary care should be considered. The *Alzheimer's Society* report found that only 12% of nurses felt that they had enough pre-registration training in dementia, 76% of nurse managers said that the fact that nursing staff had not been given pre-registration training in dementia was a key challenge in providing good dementia care.

Recommendation: Members of the secondary care team, including reception staff, should receive appropriate training to respond appropriately to people with dementia and their carers.

11. Community health care for people with dementia

This element of the patient pathway is linked to general practice and social care. For primary care for people with dementia also includes input from community psychiatric nurses (CPN), district nurses, and community matrons; these services are now provided by LPT, and they are commissioned by local NHS. The services also include intermediate care provision, which is defined as a short term intervention limited to 6 weeks, which are now provided by LPT in conjunction with Leicester City Council, and commissioned by NHS Leicester City and Leicestershire County and Rutland.

District nursing and community matrons look after physical health care needs, and are likely to be involved in dementia care only if the person with dementia or their carer has a physical health requirement. This important nursing resource is also likely to be particularly important in the delivery of end of life care.

Intermediate care aims to support people on discharge from hospital, before they are able to go home, and also to avoid hospital admissions. Access to Intermediate Care support is for people living at home and in residential care. There are limitations in access to people living with dementia; a strange environment can exacerbate the symptoms of confusion associated with dementia, the Intermediate Care teams do not necessarily have support of a CPN and access to some community hospital beds is inconsistent.

In Leicester there are two facilities available to people needing short-term support, including those with dementia. This is delivered from Brookside Court and Elizabeth House. Brookside Court offers 12 reablement beds and 9 intermediate care beds. Elizabeth House offers a residential care assessment centre service for up to 6 weeks, to help determine an individual’s long-term care needs. As the ultimate aim of this service is to support people to regain their independence, to avoid hospital admission and long-term residential placements where possible, this service is perhaps most appropriate for people in the earliest stages of dementia.

Although there are intermediate care and re-ablement services across LLR for both health and adult social care, the care pathways are not joined up, sometimes resulting in pressure on adult social care services, especially when dealing with hospital discharges. This situation is often compounded as services are not specifically focussed to support people with dementia or their families/carers.

Recommendation: To ensure that there is an integrated reablement and integrated care model that reflects the needs of people with dementia.

The Community Mental Health Teams for Older People are provided by LPT and Leicester City Council. In Leicester there are 2 Community Mental Health Teams (CMHTs) offering a multi-disciplinary assessment and treatment service for older people with complex mental health needs. Thus this service also offers support to older people living with a mental health condition other than dementia, such as depression. The teams include health and social care staff, who work together to support people in the community to promote independence, reduce the need for an admission to hospital and recovery following admission, and aims to reduce admission into residential and nursing care.

The health and social care staff also collaborate in supporting people with dementia and their carers in the community. As the teams incorporate social workers, occupational therapists, and mental health expertise, they are able to support people with behavioural symptoms which result from dementia.

The community mental health care service also includes the Integrated Clinical Assessment and Treatment Service (ICATS), which is provided by LPT and commissioned by NHS Leicester City and Leicestershire County and Rutland.

The ICAT offers intensive support for people in the community, and focuses on the intensive assessment and treatment for people with both functional and organic mental health problems. It also links with the locality CMHTs and performs a number of roles including assessment, therapy, treatment and support after discharge from hospital, monitoring patients, facilitating groups and services to carers.

At present there are no support services that provide specialist mental health care at times of crisis for people with dementia and their carers, out of normal operating hours. As a result, if a problem arises outside the operating hours for these services, it can lead to unnecessary admission to hospital to support the patient and family/carers.

Recommendation: Review the existing ICATS model of delivery, to develop a service focused on preventing admission to the older person’s mental health inpatient wards, and facilitate timely discharge from in-patient care.

Recommendation: Review the options for commissioning a joint health and social care crisis response service, to support both users and their families/carers.

12. Medication for Alzheimer’s disease

12.1 Medication in Alzheimer’s disease

As there is no cure for Alzheimer’s disease, current medication focuses on treating symptoms. This medication does not aim to slow the progression of the disease, but Drugs may be prescribed to dementia patients to slow the rate of cognitive decline. Acetylcholinesterase inhibiting drugs are used in the treatment of Alzheimer’s disease, specifically for mild to moderate disease. The benefit is assessed by repeating the cognitive assessment at around 3 months.

The treatment of Alzheimer’s disease includes three acetylcholinesterase (AChE) inhibitors donepezil, galantamine and rivastigmine, which are recommended as options for managing mild to moderate Alzheimer’s disease, and memantine, which is recommended as treatment for those with severe Alzheimer’s disease or as an option for managing people with moderate disease who are intolerant of or have a contraindication to AChE inhibitors.

Currently there are special conditions in which such treatment should be used, and these including:

- Treatment should only be initiated by specialists in dementia care. These include psychiatrists, such as those specialising in learning disability, neurologists, and physicians specialising in the care of older people.
- The continuation of this treatment should be considered only if it is seen to be having a worthwhile effect on a person’s cognitive, global, functional or behavioural symptoms.
- Patients who continue on treatment should be reviewed regularly using a cognitive, global, functional and behavioural assessment.
- Unless there are locally agreed protocols for shared care this treatment should be reviewed by an appropriate specialist team.
- Carers’ views on the patient’s condition should also be sought at the time of the baseline and follow up assessments.

The latest NICE technical guidance suggests that if an AChE inhibitor is prescribed then the drug with the lowest acquisition cost, taking into account the daily dose and the price per dose once shared care has started, should be the first course of treatment (the costs of treatment are presented in Appendix 13). However, an alternative AChE inhibitor could be prescribed if it is considered appropriate, based on clinical judgements such as adverse events, adherence, medical co-morbidity, the possibility of drug interactions and dosing profiles.

Clinicians are encouraged to use a range of appropriate evidence to assess a patient with Alzheimer’s disease and the need for treatment. This includes cognition scores, assessments of any physical, sensory or learning disabilities, and communication difficulties. Clinicians are also encouraged to be mindful of the need to secure equality of access to treatment for patients from different ethnic and cultural backgrounds and make any adjustments that they consider to be appropriate.

12.2 AChE inhibitors

Of the three treatments for mild to moderate Alzheimer’s disease, Rivastigmine (Exelon) and Donepezil (Aricept) are AChE inhibitors which work by increasing the concentration of acetylcholine at sites of neurotransmission. Galantamine (Reminyl) is an AChE inhibitor, which works both by increasing the concentration of acetylcholine at sites of neurotransmission and modulates activity at nicotinic receptors.

The NICE guidance committee considered evidence from randomised controlled trials that these medications are effective when compared to a placebo. For instance, trails with Donepezil and Galantamine showed a showed a statistically significant difference in their favour versus placebos. For both Donepezil and Galantamine there were trials which reported statistically significant benefits to patients when cognitive scales were used. A Cochrane review concluded that high doses of Rivastigmine offered statistically significant benefits in patients with mild to moderate Alzheimer’s disease versus placebo.

A key driver of cost effectiveness in the NICE Guidance was treatment which leads to a delay in institutionalisation. According to the guidance, the evidence suggested AChE inhibitors offer benefits over best supportive care for cognitive, functional and global outcomes, and may offer some benefit in behavioural outcomes, although the nature and extent of behavioural benefits are uncertain. When compared with best supportive health and social care each of the AChE inhibitors showed a cost saving.

12.3 Memantine

The fourth treatment, Memantine (Ebixa) is recommended as an option for managing Alzheimer’s disease for people with moderate Alzheimer’s disease who are intolerant of or have a contraindication to AChE inhibitors, or for people with severe Alzheimer’s disease. It is an N-methyl-D-aspartate (NMDA) receptor antagonist that blocks the effects of pathologically elevated tonic levels of glutamate that may lead to neuronal dysfunction. It is in effect a glutamate moderator. One of the reasons

The NICE Guidance Committee considered the results of randomised controlled trials for Memantine and concluded that it offers symptomatic benefit in cognitive, functional, global and behavioural outcomes, although the size of this benefit is uncertain. It also looked at evidence for the clinical effectiveness of Memantine as an adjunct to AChE inhibitor treatment but noted that there was no statistically significant benefit for combination treatment with Memantine and AChE inhibitors for cognitive, functional, behavioural or global outcomes.

Antipsychotic medications (also known as neuroleptics or major tranquillisers) are also used for the treatment of restlessness, aggression and psychiatric symptoms in people with dementia. Clinical trials suggest that this type of drug can reduce aggression and, to a lesser extent, psychotic symptoms over a period of three months. However, there is no evidence that these drugs improve restlessness or other non-aggressive behavioural symptoms[138] [139]. Clinical trials show that the benefits are very limited over longer periods[140]and that such medication can be safely stopped after three months, with no worsening of behavioural symptoms in most people[141]. The two drugs with the best evidence of effectiveness are Risperidone and Aripiprazole[142] [143]of which Risperidone, has been licensed specifically for the treatment of severe and persistent aggression in people with Alzheimer's disease that have not responded to other therapies. However, clinicians say that the use of some anti-psychotic medication is essential for some people with dementia. There is no evidence of any beneficial effects of antipsychotic medication for the symptoms of people with dementia with Lewy bodies, and there are currently no clinical trials looking at these drugs in people with vascular dementia.

There is an impetus to reduce the number of people with dementia who have been prescribed anti-psychotic medication. In particular, the use of Memantine for cases of moderate to severe dementia may enable this to happen, although there is a risk to prescribing budgets. As Memantine is a glutamate moderator, it may protect neurological functions and improve behavioural symptoms. The latest NICE technical guidance suggests therefore that Memantine will be the first line treatment to manage the behavioural symptoms associated with some dementias.

12.4 Cost of dementia medication in Leicester

The cost of prescribing drugs for dementia shows a general upward trend over the time period 2008-09 to 2010-11. As the treatments should currently only be initiated by those who specialise in dementia care, the costs are attributed to the memory assessment service, with a limited amount currently in primary care. Table 12.1 below show the quarter spend on medication for Alzheimer's disease for 2010-11. The total spend for the period was £385,924.29 for 2048 patients.

Table 21.1: Cost of prescribing drugs for dementia

	Quarter 1			Quarter 2			Quarter 3			Quarter 4		
2010-11	No. of Patients	No. of Items	Actual Cost	No. of Patients	No. of Items	Actual Cost	No. of Patients	No. of Items	Actual Cost	No. of Patients	No. of Items	Actual Cost
Donepezil	95	124	£22,584.01	94	125	£24,388.74	86	120	£20,440.55	81	108	£21,604.39
Galantamine	277	381	£47,840.17	286	393	£53,308.93	297	447	£54,699.00	308	436	£60,383.31
Memantine	53	83	£12,541.11	56	79	£11,678.51	65	103	£17,033.66	83	102	£18,460.85
Rivastigmine	25	38	£5,320.15	24	35	£6,019.25	21	31	£4,794.32	21	25	£4,827.34
Totals	450	626	£88,285.44	460	632	£95,395.43	469	701	£96,967.53	493	671	£105,275.89

13. Future direction for commissioning dementia care

Commissioning dementia services is a rapidly developing area, with many national commitments offering opportunities for the development of effective interventions. The new services are centred upon primary care, with the improvement in rates of diagnosis part of the NHS Outcomes Framework. This JSpNA has shown that the future direction includes:

Increasing rates of diagnosis: The commissioning challenge for the Clinical Commissioning Group is to ensure that primary, secondary and specialist dementia health care have a recognised role in the diagnosis of dementia and that the diagnosis is effectively communicated to primary health care as the holders of the registers of people with dementia and their carers.

Deciding where the diagnosing takes place: This issue relates to the best use of expertise in memory assessment and secondary care, and the capacity of primary care services to be involved in early recognition. The costs of treatment should become clearer with the move to payment by results in mental health care.

Ensuring that there is a credible patient pathway following diagnosis; The future direction here is for health and social care commissioners to work closely together to build a patient pathway which offers quality care and credible support for care recipients and their carers. This should reduce the costs of acute hospital care and care home admission and

Appropriate prescribing: Commissioners will need to work with primary, secondary and specialist care areas to review patients' medication and to reduce the inappropriate prescribing of anti-psychotic medication. They may be able to use CQUIN schemes to do this.

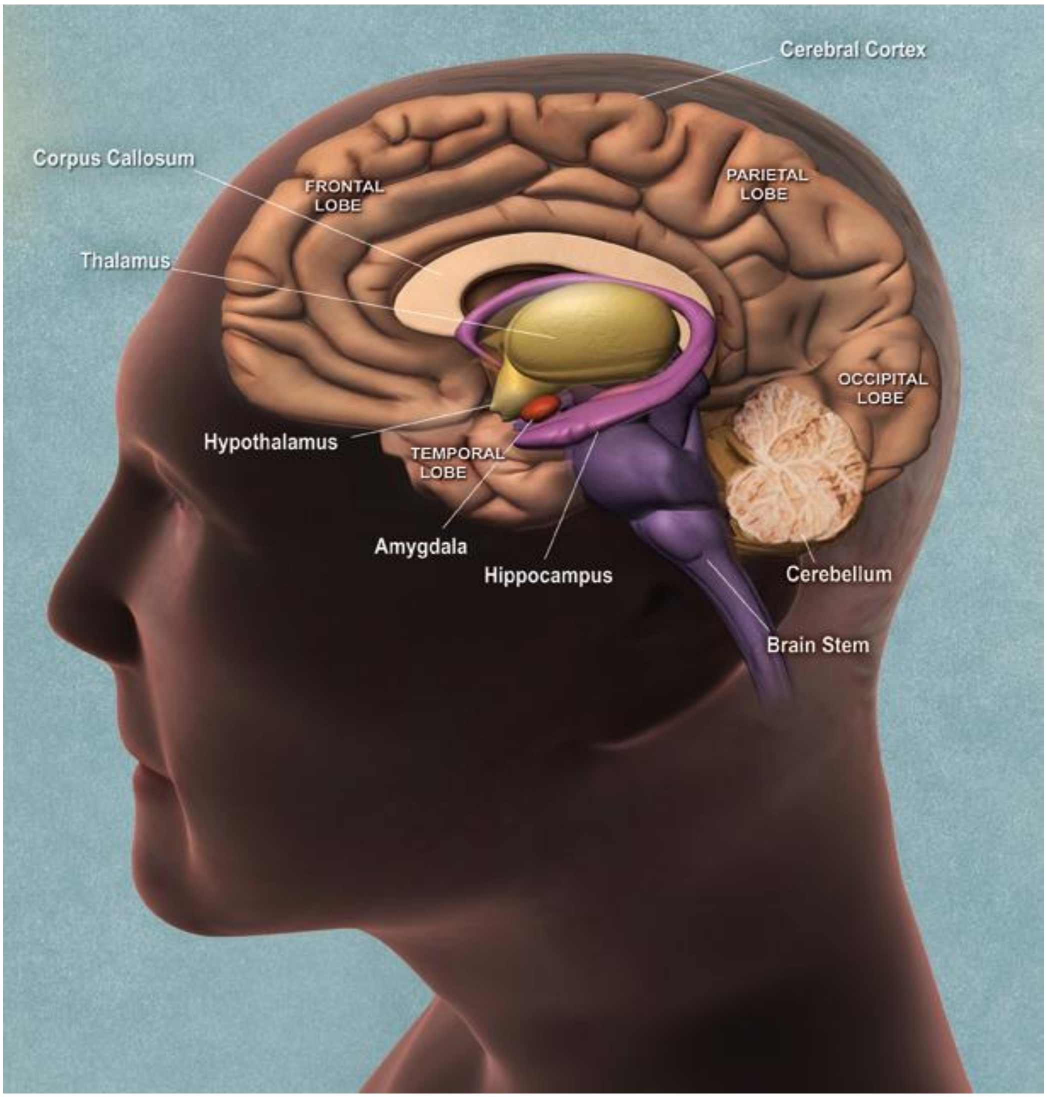
Ensuring that the dementia care workforce is able to deliver high quality care: As the care of people with dementia has an impact across many different health and social care services, it is crucial that the workforce is trained in the common core principle for supporting people with dementia.

14. Appendices

14.1 Appendix 1: The brain

Dementia is one of many disorders which affect the brain and central nervous system. Changes, related to normal ageing, occur in the brain as a person gets older[144]. These changes may mean that there is a slight decline in an older person's ability to learn new things or remember information. However, the changes which are related to dementia are more severe.

Figure 1: Lateral view of the human brain[145]



Blood supply to the brain must be continuous. Although the brain constitutes about 2% of the human body, it uses about 20% of the oxygen supply[146]. Any interruption of the supply of blood to the brain is likely to result in unconsciousness. The blood supply to the brain also contains glucose for energy. If the blood circulating to the brain is low in glucose then confusion, dizziness, convulsions and unconsciousness may result.

The cerebral hemispheres account for most of the weight of the brain. They are principally connected by a bundle of transverse fibres called the corpus callosum. The left hemisphere helps a person to focus on details, such as face recognition, whilst the right is concerned with broad background, such as the relative position of objects in space.

Each cerebral hemisphere is subdivided into four lobes by fissures; the lobes are also related to different functions. The frontal lobe controls functions such as memory, thought, organisation and movement. The parietal lobe is linked to perception and sensory information; the occipital lobe is concerned with vision and the temporal lobe, with smell, taste and sound.

The cerebellum is divided into hemispheres and lobes. It is widely accepted to be a motor area of the brain[147], concerned with certain subconscious movements in the skeletal muscles. These are movements which are required for co-ordination, maintenance of posture and balance[148]. Recent studies have also suggested that the cerebellum is important area for a person's emotions[149].

The brain stem consists of the medulla oblongata, pons varolii and the midbrain. The lower end of the brain stem is a continuation of the spinal cord. It controls those functions which keep a person alive, such as the heart rate and breathing. The medulla oblongata conducts motor and sensory impulses between the brain and the spinal cord. It contains the nuclei of origin for several pairs of cranial nerves concerned with hearing and balance, swallowing, salivation and taste. The pons varolii acts as a bridge between different parts of the brain and the brain and spinal cord. It also contains the nuclei for paired cranial nerves related to chewing and for the sensations of the head and face. The midbrain helps to relay auditory and visual information, and there are portions of the midbrain, called the red nucleus and the substantia nigra, which are involved in the control of body movement.

The main structures of the diencephalon are the thalamus and the hypothalamus. The thalamus is a structure above the mid brain in which some sensations, such as pain, temperature and pressure are interpreted. The hypothalamus is a structure below the thalamus which is related to the internal regulation of the body, homeostasis. It controls and integrates the autonomic nervous system (which is linked to functions such as heart rate, digestion, contraction of the urinary bladder); it is the link between the nervous system and the endocrine system; it is associated with feelings of rage and aggression; it controls normal body temperature; it regulates food intake and produces the sensation of thirst.

The thalamus and hypothalamus are also linked to the limbic system. This system connects the brain stem and the cerebral cortex. It controls emotional aspects of behaviour which are linked to survival, such as pain, pleasure, docility, sexual feelings and affection. Other components of the limbic system include the hippocampus, which is important for short term memory and learning, and the amygdaloid nucleus which is linked to fear.

Neurons are composed of a cell body, the axon, and dendrites. Neurons communicate with each other through axons and dendrites. Once at the end of an axon the signal reaches a synapse, a gap, which is overcome either by an electric impulse or a chemical messenger, called a neurotransmitter. There are over 40 transmitter substances in the brain[150].

Acetylcholine (ACh) is a transmitter released by neurons throughout the body. As long as it is present at the junction between a muscle and a nerve it can stimulate or excite a muscle fibre almost indefinitely. The transmission of a continuous succession of impulses by ACh is prevented by an enzyme called Acetylcholinesterase (AChE) or cholinesterase. There is evidence that a deficiency in ACh is linked to dementia[151].

Other neuro-transmitters have been found to have an association with different illnesses. Dopamine is a transmitter which leads to excitation, emotion and subconscious movements of skeletal muscles. Neurons containing dopamine are located in the midbrain. In Parkinson's disease the neurons which release dopamine have been found to have degenerated. Serotonin is a transmitter, concentrated in the brain stem, the production of which leads to excitation. It is known to modulate mood, emotion, sleep and appetite and thus is implicated in the control of numerous behavioural and physiological functions. Decreased transmission of serotonin is thought to play a key role in the aetiology of depression[152].

14.2 Appendix 2: National Dementia Strategy Objectives

1. Raise awareness of dementia and encourage people to seek help

Public and professionals will be more aware of dementia and will understand dementia better. This will:

- Help remove the stigma of dementia
- Help people understand the benefits of early diagnosis and care
- Encourage the prevention of dementia
- Reduce other people's fear and misunderstanding of people with dementia

2. Good-quality, early diagnosis, support and treatment for people with dementia and their carers, explained in a sensitive way

All people with dementia will have access to care that gives them:

- An early, high-quality specialist assessment
- An accurate diagnosis which is explained in a sensitive way
- Treatment, care and support as needed after the diagnosis
- Local services which are able to see all new cases promptly

3. **Good-quality information for people with dementia and their carers**

- People with dementia and their carers will be given good quality information about dementia and the services available at diagnosis and during their care

4. **Easy access to care, support and advice after diagnosis**

- People with dementia and their carers will be able to see a dementia adviser who will help them throughout their care to find the right information, care, support and advice

5. **Develop structured peer support and learning networks**

People with dementia and their carers will be able to:

- Get support from local people with experience of dementia
- Take an active role in developing local services

6. **Improve community personal support services for people living at home**

- There will be a range of flexible services to support people with dementia living at home and their carers
- Services will consider the needs and wishes of people with dementia and their carers

7. **Implement the New Deal for Carers**

- Carers will have an assessment of their needs, get better support and be able to have good quality short breaks from caring

8. **Improve the quality of care for people with dementia in general hospitals**

People with dementia will get better care in hospital because:

- It will be clear who is responsible for dementia in general hospitals and what their responsibilities are
- The people responsible for care will work closely with specialist older people's mental health teams

9. **Improve intermediate care for people with dementia**

- There will be more care for people with dementia who need help to stay at home

10. **Consider how housing support, housing related services, technology and telecare can help support people with dementia and their carers**

Services will:

- Consider the needs of people with dementia and their cares when planning housing and housing services
- Try to help people to live in their own homes for longer

11. Improve the quality of care for people with dementia in care homes

Services will work to ensure:

- Better care for people with dementia in care homes
- Clear responsibility for dementia in care homes
- A clear description of how people will be cared for in care homes
- That there will be visits from specialist mental health teams
- Better checking of care homes

12. Improve end of life care for people with dementia

- People with dementia and their carers will be involved in planning end of life care
- Services will consider people with dementia and their carers when planning local end of life services

13. An informed and effective workforce for people with dementia

- All health and social care staff who work with people with dementia will have the right skills to get the right care, get the right training and get support to keep learning about dementia

14. A joint commissioning strategy for dementia

- Health and social care services will work together to develop systems to identify the needs of people with dementia and their carers best meet these needs

15. Improve assessment and regulation of health and care services and of how systems are working

- There will be better checks on care homes and other services to make sure people with dementia get the best possible care

16. Provide a clear picture of research about the causes and possible future treatments of dementia

- People will be able to get information from research about dementia
- Identify gaps in research information and do more to fill the gaps

17. Effective national and regional support for local services to help them develop and carry out the strategy

- More good quality information to develop better local services for people with dementia

14.3 Appendix 3: End of life care strategy

The *End of Life Care Strategy* suggests that for most people high quality end of life care should include:

- Being treated as an individual, with dignity and respect
- Being without pain and other symptoms
- Being in familiar surroundings
- Being in the company of close family and/or friends

In the light of these factors, the *End of Life Care Strategy* aims to ensure that people have the opportunity to discuss their personal needs and preferences with professionals. It is envisaged that all health and social care staff will be trained in communication regarding end of life care, in assessing the needs of patients and carers and, where necessary, reconciling differing requirements. Thus, according to the *End of Life Care Strategy* the discussions of preferences will be recorded in a care plan so that every service involved will be aware of peoples' priorities and will take account of their preferences.

The aim of recording such needs and preferences in a care plan is to coordinate care and support; ensuring that needs are met, irrespective of who is delivering the service:

- Every organisation involved in providing end of life care will be expected to adopt a coordination process, such as the Gold Standards Framework
- Local end of life care coordination centres will be established to coordinate care across organisational boundaries
- End of life care registers will be piloted and established to ensure that every organisation which will be involved in care is aware of a patient's wishes

The *End of Life Care Strategy* envisages a rapid specialist advice and clinical assessment wherever a patient may be, including:

- Access to dedicated 24/7 telephone help lines and rapid access homecare services
- Specialist palliative care outreach services to be established in every area

The high quality care and support during the last days of a person's life was envisaged to include:

- A care pathway approach for management of the last days of life, such as the Liverpool Care Pathway[153], across England
- Facilities to be provided to support relatives and carers who wish to stay with a patient in hospital

The strategy also suggests that end of life care will be monitored and assessed to ensure quality, with best practice being identified and spread so that others may benefit. As part of this,

- A national intelligence network will be established to collect, analyse and publish data on service quality performance
- A dedicated multi-professional national support team will work with commissioners and providers to identify and spread good practice
- Surveys of bereaved relatives and carers will be introduced
- Comprehensive analysis of complaints relating to end of life care will be undertaken
- The national *End of Life Care Research Initiative* will be launched to improve understanding of how best to care for people reaching the end of their life and support those caring for them.

14.4 Appendix 4: Dignity in Care 10 Point Dignity Challenge

The *Dignity in Care* campaign was launched following a number of listening events around the country to find out what dignity in care meant to different people. The issues raised at these events resulted in the development of the 10 point Dignity Challenge. The challenge depicts what high quality services that respect people's dignity should include:

- Zero tolerance of all forms of abuse
- Supporting people with the same respect you would want for yourself or a member of your family
- Treating each person as an individual by offering a personalised service
- Enabling people to maintain the maximum possible level of independence, choice and control
- Listening and supporting people to express their needs and wants
- Respecting a person’s right to privacy
- Ensuring people feel able to complain without fear of retribution
- Engaging with family members and carers as care partners
- Assisting people to maintain confidence and a positive self-esteem
- Acting to alleviate people's loneliness and isolation.

14.5 Appendix 5: Local Policy 23 objectives

The 5 local work streams are tasked to deliver 23 objectives:

1. To increase early diagnosis and access to interventions for people with dementia
2. To commission a single point of contact for people living with dementia at each step of the care pathway to improve access to advice and services
3. To strategically review the pathway for memory assessment and commission a service that is integrated into a health and social care pathway
4. Improved management of causes of behavioural and psychological symptoms in dementia via a LLR wide implementation of prescribing guidelines
5. To commission a shared model of care allowing prescribing in both primary and secondary care to benefit those living with dementia and encourage service efficiency
6. To review the existing ICATs model of delivery to develop a service focused on preventing admission to the older people's mental health in-patient wards and facilitate timely discharge
7. To review options for commissioning a joint health and social care crisis response service to support people with dementia and their families/carers
8. To commission an integrated intermediate care model across health and social care that is able to support GPs to look after the physical health care needs of people with dementia
9. To commission integrated reablement services that reflects the specialist needs of people with dementia and delivers a pathway that reduces hospital admissions and reduces delayed discharges
10. To develop an integrated health and social care community based pathway to reduce length of stay in hospital, reduces the need for hospital admission and is able to meet the mental and physical health care needs of people with dementia
11. To ensure consistent detection of dementia within a hospital setting and the development of appropriate care pathways
12. To ensure all family carers have access to dementia support services as early as possible and to ensure that a carers assessment is completed
13. To commission a range of respite services to support carers in their caring role
14. To ensure that people with dementia are given a personal budget if eligible of support and that self funders are given appropriate advice and information about services available to them
15. To develop community based dementia services to allow people to use their personal budgets
16. To increase specialist dementia home care and ensure it is high quality and enables choice and control for the individual
17. To ensure that the use of assistive technology is embedded into care pathways across health and social care
18. To ensure that housing strategies commission life time community based accommodation that can support older people and those with dementia

19. To ensure that all people diagnosed with dementia have access to advice and information
20. To ensure that all services that are commissioned meet a range of quality standards including NICE and CQC
21. LLR wide implementation of prescribing guidelines
22. Review access to specialist support and other in-reach for people living in care homes
23. Ensure that workforce is commissioned to deliver services to support the care pathway for dementia

These objectives are expected to:

- Increase in the proportion of people with dementia receiving a diagnosis while they are in the early stages of the illness
- Increase in the proportion of people with dementia having a formal diagnosis compared with the local estimated prevalence
- Increase in the number of patients and carers who have a positive service experience
- Reduce the average length of stay in hospital for patients with dementia
- Reduce the number of people with dementia discharged directly from hospital to care homes as a new place of residence
- Reduce the number of people discharged from hospital on antipsychotic medication
- Increase the number of people having a plan to review use of antipsychotic medication post discharge
- Reduce the use of antipsychotic medication for people with dementia in care homes, at home and other residential settings
- Contribute to a reduction in unplanned admissions and readmissions of people with dementia to general and community hospitals
- Achieve better care at home and in residential care

14.6 Appendix 6: Projections by ethnic group

Leicester currently has a population which is younger than the national average. The population of the city is also characterised by young, ethnic minority populations. Over time, these ethnic minority groups will age, so that they will form a larger proportion of the elderly population. This will have an impact on the service provision.

14.6.1 Projection method

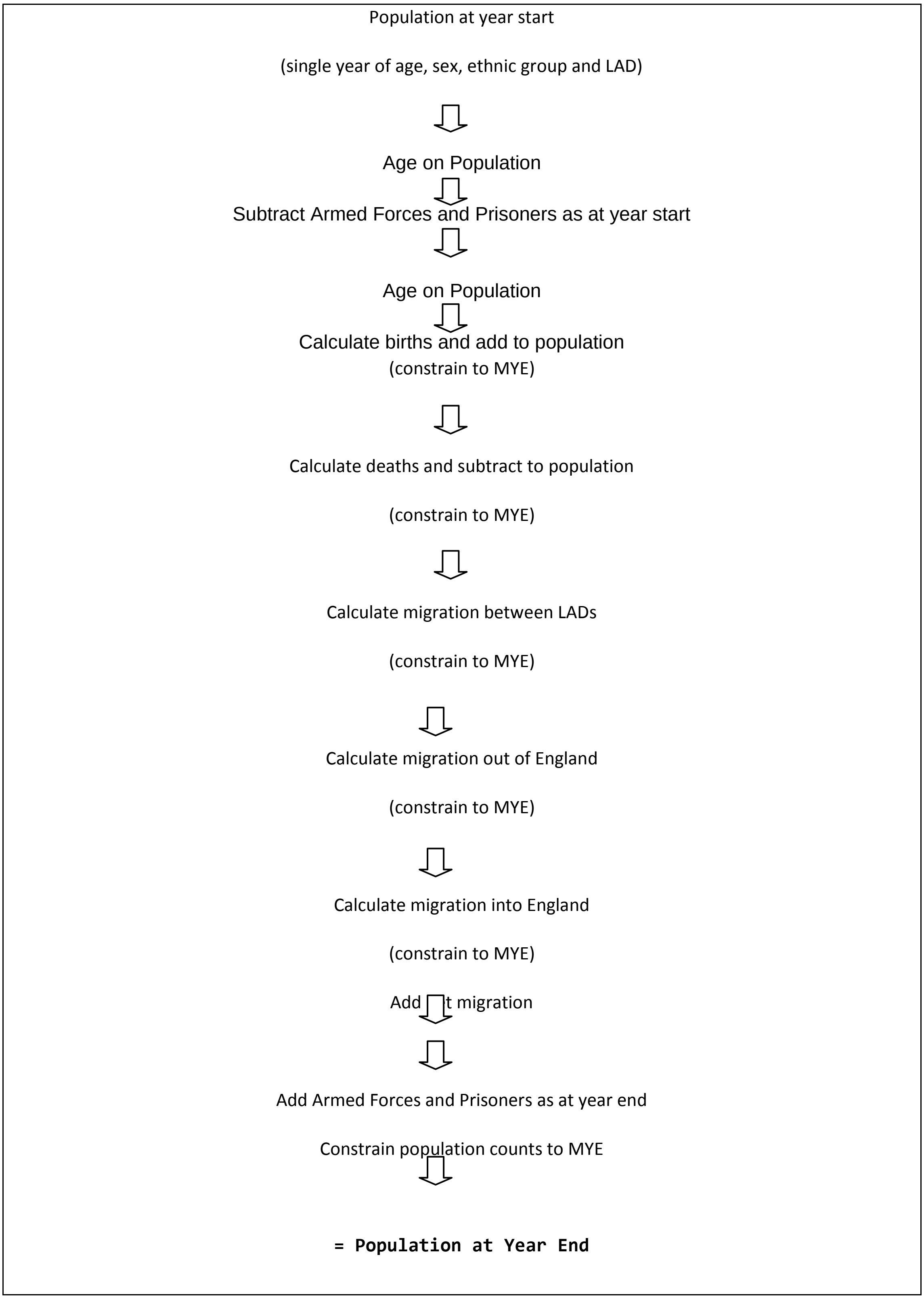
The population projections in are based on the 'aging on' of population at the start of the year, with adjustments for members of the armed forces and prisoners, births, deaths, migration in and migration out of the country. In order to estimate these projections by ethnic category, this requires completion and consistency in reporting of ethnic categories.

14.6.2 Problems with population projections by ethnic categories

Population projections by ethnic group are problematic for a number of reasons. The Census collects ethnic data by asking the population to identify themselves into one of the listed ethnic categories and there is an assumption that this will provide accurate data that can be compared overtime. However, there are reasons as to why this is not the case:

- Use of pre-determined Census ethnic categories (rather than self-identification)
- Introduction of new ethnic categories (e.g. 'Mixed' categories in 2001)
- Instability of responses to ethnic categories
- Notion of self-reporting (exceptions include Census 2001 where the respondent was asked to answer for every member in the household, births, deaths)
- Use of consistent ethnic categories across relevant datasets

Process of Producing Population Estimates by Ethnic Group



Source: Large & Ghosh (2006)[154]

14.7 Appendix 7: Classification of dementia

The International Classification of Diseases, tenth revision (ICD-10) provides the following categories of dementia:

F00 Dementia in Alzheimer's disease

F00.0 Dementia in Alzheimer's disease with early onset

F00.1 Dementia in Alzheimer's disease with late onset

F00.2 Dementia in Alzheimer's disease, atypical or mixed type

F00.8 Dementia in Alzheimer's disease, unspecified

F01 Vascular dementia

F01.0 Vascular dementia of acute onset

F01.1 Multi-infarct dementia

F01.2 Sub-cortical vascular dementia

F01.3 Mixed cortical and sub-cortical vascular dementia

F01.8 Other vascular dementia

F01.9 Vascular dementia, unspecified

F02 Dementia in other diseases classified elsewhere

F02.0 Dementia in Pick's disease

F02.1 Dementia in Creutzfeld-Jakob's disease

F02.2 Dementia in Huntingdon's disease

F02.3 Dementia in Parkinson's disease

F02.4 Dementia in human immunodeficiency virus (HIV) disease

F02.8 Dementia in other diseases classified elsewhere

F03 Unspecified dementia

14.8 Appendix 8: Planning effective respite

A Good Break

Maintenance or Improvement of the carer's health, well-being and/or quality of life

Effective respite services and short-term breaks are:

Based on assessment and on-going review	Appropriate to the need and circumstances of the carer	Appropriate to the age culture, condition and stage of illness for the care recipient	Able to maintain or improve the well-being of the care recipient	Delivered by appropriately trained and caring staff	Affordable to the carer

Effective respite services and short-term breaks are underpinned by:

Knowledge-able and supportive doctors	Appropriate management of the condition (e.g. medication and equipment)	Responsive social services	Accessible information	Fair and easy to understand benefits and charging systems	Well-coordinated services	Supportive carers networks	**Helpful family, friends and neighbours**

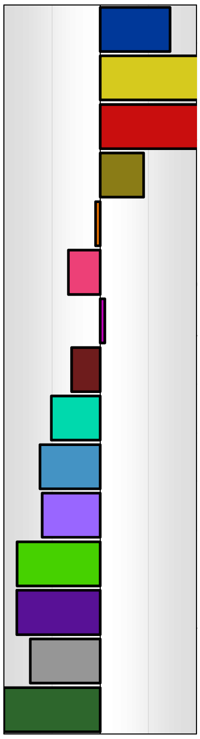
14.9 Appendix 9: Potential patient outcomes from the memory assessment service

Outcome	Action
1. No illness	Advise outcome of assessment to GP including any recommendations
2. Other illness (including depression)	Initiate urgent treatment or referral for physical or mental disorder if required or discharge to GP with advice on treatment or referral
3. Dementia (no medication)	Talk through timely interventions; signpost and refer to resources/support available. Advise GP of outcome and recommended next steps
4. Dementia (medication)	Talk through timely interventions, including medication. Signpost and refer to resources/support available. Advise GP of outcome and recommended next steps
5. Possible dementia (MCI)	Advise GP to re-refer if symptoms persist or increase

14.10 Appendix 10: Mosaic Groups in Leicester

Comparison of Mosaic groups in Leicester and England

	Mosaic Public Sector Groups	Leicester	%	England	%	Pen. %	Index
E	Middle income families living in moderate suburban semis	78,661	22.45	6,750,377	13.01	1.17	173
I	Lower income workers in urban terraces in often diverse areas	65,146	18.59	4,320,659	8.33	1.51	223
O	Families in low-rise social housing with high levels of benefit need	53,873	15.37	2,956,632	5.70	1.82	270
G	Young, well-educated city dwellers	44,803	12.79	4,567,853	8.80	0.98	145
K	Residents with sufficient incomes in right-to-buy social housing	30,378	8.67	4,718,598	9.10	0.64	95
J	Owner occupiers in older-style housing in ex-industrial areas	18,895	5.39	4,183,126	8.06	0.45	67
N	Young people renting flats in high density social housing	17,546	5.01	2,480,603	4.78	0.71	105
M	Elderly people reliant on state support	8,968	2.56	1,887,321	3.64	0.48	70
H	Couples and young singles in small modern starter homes	7,973	2.28	2,396,762	4.62	0.33	49
F	Couples with young children in comfortable modern housing	7,539	2.15	2,962,555	5.71	0.25	38
C	Wealthy people living in the most sought after neighbourhoods	4,963	1.42	1,848,118	3.56	0.27	40
B	Residents of small and mid-sized towns with strong local roots	4,168	1.19	4,498,119	8.67	0.09	14
D	Successful professionals living in suburban or semi-rural homes	4,123	1.18	4,504,874	8.68	0.09	14
L	Active elderly people living in pleasant retirement locations	3,397	0.97	1,836,109	3.54	0.19	27
A	Residents of isolated rural communities	0	0.00	1,968,327	3.79	0.00	0
Total		**350,433**	**100**	**51,880,033**	**100**	**0.68**	**100**



14.11 Appendix 11: Actions in the Prime Ministers challenge on dementia

Driving improvements in health and care

- Increase diagnosis rates through existing checks for over-65s ensuring that GPs and other health professionals make patients aged 65 and over aware of memory clinics and refer those in need of assessment. From April 2013, there will be a quantified ambition for diagnosis rates across the country, underpinned by robust and affordable local plans.
- Financial rewards for hospitals offering quality dementia care From April 2012, £54m will be available through the Dementia CQUIN payment framework to hospitals offering dementia risk assessments to all over-75s admitted to their care. From April 2013, this will be extended to the quality of dementia care delivered. Also, for April 2013 access to all CQUIN rewards will be dependent on delivering support for carers in line with the NICE/SCIE guidelines.
- An Innovation Challenge Prize of £1m NHS staff can win up to £1m for innovative ideas for transforming dementia care.
- A Dementia Care and Support Compact signed by leading care home and home care providers
- Promote the information offer pioneered by the NHS South West, which will be launched on 28 March 2012 and rolled out across the south by the end of 2012 From April 2013, information will be available in all other parts of the country. We will also be setting out in the Care and Support White Paper further steps to ensure all people receiving care and support get better information to support their care choices.
- Work with profession to identify how best to improve early diagnosis of dementia through improvements in awareness, education and training and through potential improvements to the GP contract.
- Ask NICE to consider ways of improving the dementia indicators in the Quality and Outcomes Framework.
- Call on the Royal Colleges to respond to the challenge of dementia by bringing forward plans to ensure that all their members are capable and competent in dementia care. The Royal Colleges have committed to driving this forward.
- Ensure that memory clinics are established in all parts of the country, and work with the Royal College of Psychiatrists to drive up the proportion of memory services that are accredited, through publication of their national Memory Services Accreditation Programme, so that individual organisations can benchmark and report their own performance to drive improvement The NHS will guarantee a written integrated personalised care plan to people with dementia.
- Better support for carers with the NHS required to work closer than ever before with local carers' organisations and councils to agree plans, pool their resources, and make sure that carers get the support and break they deserve and that young carers do not take on excessive or inappropriate caring roles
- Carers have the right to be assessed and their needs met carers can take their support as a personal budget and should be encouraged so to do. The NHS should also ensure that a range of psychological therapies are commissioned and made available to carers of people with dementia in line with NICE/SCIE guidelines, as well as ensuring services are made available to support the couple relationship where one person is caring for a partner with dementia.
- Launch pilots of dementia clinical networks aimed at spreading clinical expertise by September 2012
- Create dementia friendly communities across the country

- Support from leading businesses for the PM’s Challenge on Dementia Leading national organisations have already pledged to look at how they and others can play a part in creating a more dementia-friendly society and raising awareness of dementia.
- Awareness-raising campaign From autumn 2012, there will be a nationwide campaign to raise awareness of dementia, to be sustained to 2015. This will build on lessons learned from previous pilot campaigns and will inform future investment.
- A major event over the summer, bringing together UK leaders from industry, academia and the public sector, to take forward the PM’s Challenge on Dementia.
- Work with the Alzheimer’s Society to develop local Dementia Action Alliances to bring together people with dementia, their carers and key organisations, funded by £537,000 from the Department of Health over three years.
- Make sure that people with dementia and carers on diagnosis have an information pack about dementia produced in conjunction with the Alzheimer's Society. The Dementia-friendly Communities Programme working in partnership with the Dementia Action Alliance will develop evidence on what a dementia-friendly community is.

Better research

With a number of initiatives, including:

- The PM’s Challenge includes a commitment to more than double overall funding for dementia research to over £66m by 2015.
- Major investment in brain scanning
- £13m funding for social science research on dementia (NIHR/ESRC) including £3m for public health research.
- £36m funding over 5 years for a new NIHR dementia translational research collaboration to pull discoveries into real benefits for patients. F
- The MRC will spend over £3m in supporting the UK brain bank network, which connects all the UK brain banks for the benefit of donors, researchers and future patients This includes £500k a year to improve the process for donation of brain tissue by meeting the costs of collecting brain tissue through the NHS, so smoothing the pathway to donation.
- A major event will be staged for pharmaceutical and biotech companies to showcase the benefits of conducting dementia research in the UK, and to assess how best to remove barriers.
- Up to £9m of DH funding will be made available for research into ‘living well with dementia’ and the delivery of dementia care. The DH will increase its support for capacity-building in dementia research, focusing on nurses as well as doctors.

14.12 Appendix 12: The Common Core Principles for Supporting People with Dementia

- Principle 1: Know the early signs of dementia.
- Principle 2: Early diagnosis of dementia helps people receive information, support and treatment at the earliest possible stage.
- Principle 3: Communicate sensitively to support meaningful interaction.
- Principle 4: Promote independence and encourage activity.
- Principle 5: Recognise the signs of distress resulting from confusion and respond by diffusing a person's anxiety and supporting their understanding of the events they experience.
- Principle 6: Family members and other carers are valued, respected and supported just like those they care for and are helped to gain access to dementia care advice.
- Principle 7: Managers need to take responsibility to ensure members of their team are trained and well supported to meet the needs of people with dementia.
- Principle 8: Work as part of a multi-agency team to support the person with dementia.

14.13 Appendix 13: Cost of medications for Alzheimer's disease

Donepezil is initially given at 5 mg once daily at night. After 1 month the treatment should be assessed, and the dose can be increased to a maximum of 10 mg once daily if necessary. Common undesirable effects include diarrhoea, muscle cramps, fatigue, nausea, vomiting and insomnia. Donepezil is available as tablets and orodispersible tablets. Net prices are stated. The cost of tablets is £59.85 (5 mg, 28-tablet pack) and £83.89 (10 mg, 28-tablet pack). The cost of orodispersible tablets is £59.85 (5 mg, 28-tablet pack) and £83.89 (10 mg, 28-tablet pack)[155]. As the patent for Donepezil will expire on February 13th 2012[156], the price structure for Donepezil is due to change.

The formulation of Galantamine which is most frequently prescribed is a capsule given initially at 8 mg once daily for 4 weeks and then increased to 16 mg once daily for at least 4 weeks. Maintenance treatment is 16–24 mg once daily depending on assessment of clinical benefit and tolerability. An older tablet formulation and a liquid preparation are also available to be given twice a day, see the summaries of product characteristics for more information. Common undesirable effects include nausea and vomiting. The cost of tablets is £68.32 (8 mg, 56-tablet pack) and £84.00 (12 mg, 56-tablet pack). Oral solution (4 mg/ml, 100 ml) costs £120.00. Modified release capsules cost £51.88 (8 mg, 28-capsule pack), £64.90 (16 mg, 28-capsule pack) and £79.80 (24 mg, 28-capsule pack).

Rivastigmine is initially prescribed at 1.5 mg twice daily and may be increased in steps of 1.5 mg twice daily at intervals of at least 2 weeks according to tolerance up to a maximum dose of 6 mg twice daily. Alternatively rivastigmine patches are available, initially using a 4.6-mg patch per day. This can be increased to a 9.5-mg patch per day for at least 4 weeks. Common undesirable effects are mainly gastrointestinal including nausea and vomiting. Rivastigmine is available as capsules, oral solution and patches. The cost of 1.5 mg rivastigmine capsules is £33.25 (28-capsule pack) and £66.51 (56-capsule pack); 3 mg capsules cost £33.25 (28-capsule pack) and £66.51 (56-capsule pack); 4.5 mg capsules cost £33.25 (28-capsule pack) and £66.51 (56-capsule pack); 6 mg capsules cost £33.25 (28-capsule pack) and £66.51 (56-capsule pack). Oral solution costs £99.14 (2 mg/ml, 120 ml). Patches cost £77.97 (4.6 mg/24 hours, 30 patches) and £77.97 (9.5 mg/24 hours, 30 patches).

Memantine is initially given as 5 mg once daily and then increased in steps of 5 mg at weekly intervals to a maximum of 20 mg daily. Common undesirable effects are dizziness, headache, constipation, somnolence and hypertension. For full details of side effects and contraindications, see the summaries of product characteristics. Memantine is available as tablets and oral drops. 10 mg memantine tablets cost £34.50 (28-tablet pack), £69.01 (56-tablet pack) and £138.01 (112-tablet pack). 20 mg tablets cost £69.01 (28-tablet pack). A treatment initiation pack (7 × 5 mg, 7 × 10 mg, 7 × 15 mg, and 7 × 20 mg tablets) costs £43.13. Oral drops (10 mg/g) cost £61.61 for 50 g and £123.23 for 100 g.

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